

RESILIENCE FACTORS IN FAMILIES CARING FOR A FAMILY MEMBER
DIAGNOSED WITH DEMENTIA

MELANIE DEIST

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Arts (Psychology) at the University of Stellenbosch**



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DECLARATION

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SUMMARY

Dementia is a chronic illness characterised by the progressive deterioration of cognitive functions. Patients diagnosed with dementia are most often cared for by family members. Families caring for dementia patients are faced with tasks that are physically exhausting and psychologically distressing. Nevertheless, some families show resilience and are able to overcome the adversity of the illness. This study aimed to identify and explore the resilience factors these families utilised to rise above the hardships faced when caring for a demented family member. The study was based on McCubbin and McCubbin's (1996) Family Resiliency Model of Family Stress, Adjustment and Adaptation and Walsh's (2002, 2003) Family Resilience Framework. A mixed-methods approach was followed to collect data from a convenience sample drawn from the Cape Metropolitan area in the Western Cape, South Africa. The study sample comprised of families in which either a spouse ($n = 44$) was caring for a partner with dementia or adult children ($n = 47$) were caring for a parent with dementia. The family resilience factors of these subgroups were explored separately and were compared with each other. The quantitative data analysis was conducted using analyses of variance (ANOVA), Pearson's product-moment correlation coefficients, and a best-subsets multiple regression analysis. Qualitative data were analysed using thematic content analysis. These analyses revealed that positive communication patterns, acceptance, optimism, family hardiness, family connectedness, and the effective management of symptoms facilitated family adaptation in both the spouse and child subgroups. Negative patterns of communication within the family was the only variable that was inversely related to family adaptation in both family subgroups. The level of adaptation in the different family subgroups did not differ significantly, but the subgroups did differ slightly in terms of their communication patterns, coping strategies and social support avenues utilised. In addition to expanding the current literature regarding family resilience, the body of information collected in this study could be used to help families caring for dementia patients to create a family environment that maximises adjustment and adaptation. The results could also be used in the development and evaluation of intervention programmes tailored to the needs of these family subgroups.

OPSOMMING

Demensie is 'n chroniese siekte wat gekenmerk word deur die progressiewe agteruitgang van kognitiewe funksies. Pasiënte wat met demensie gediagnoseer word, word meestal deur familieleden versorg. Gesinne wat sorg vir demensiepatiënte word gekonfronteer met take wat fisies uitputtend en sielkundig ontstellend is. Tog toon sommige families volharding en is hulle in staat om die teëspoed van hierdie siekte te oorkom. Hierdie studie het gepoog om die veerkragtigheidsfaktore te identifiseer en verken wat deur families wat 'n familielid met demensie versorg, aangewend word om bo hulle omstandighede uit te styg. Die studie is gebaseer op McCubbin en McCubbin (1996) se *Family Resiliency Model of Family Stress, Adjustment and Adaptation* en Walsh (2002, 2003) se *Family Resilience Framework*. Beide kwalitatiewe en kwantitatiewe data-insamelingsmetodes is in hierdie studie gebruik. 'n Gerieflikheidsteekproef is uit die Kaapse Metropolitaanse gebied in die Wes-Kaap, Suid-Afrika gewerf en het bestaan uit gesinne waarvan eggenote ($n = 44$) vir hulle eggenoot met demensie sorg of volwasse kinders ($n = 47$) vir 'n ouer met demensie sorg. Die gesinsveerkragtigheidsfaktore van hierdie subgroepe is afsonderlik ondersoek en met mekaar vergelyk. Die kwantitatiewe data-analise is via variansieontleding (VARO), die berekening van Pearson se produkmoment-korrelasiekoëffisiënte, en beste-subset regressie-analises uitgevoer. Kwalitatiewe data is met behulp van tematiese inhoud-analise ontleed. Hierdie analises het getoon dat positiewe kommunikasiepatrone, aanvaarding van die situasie, optimisme, familie gehardheid, familie verbondenheid, en die doeltreffende bestuur van demensiesimptome familie aanpassing in beide die eggenoot- en kind-subgroepe gefasiliteer het. Negatiewe, opruiende kommunikasiepatrone binne die gesin was die enigste veranderlike wat in beide subgroepe 'n omgekeerde verwantskap met familie aanpassing gehad het. Die vlak van aanpassing in die verskillende familie subgroepe het nie beduidend verskil nie, maar die subgroepe het effens verskil in terme van hulle kommunikasiepatrone, streshanteringstrategieë, en bronne van sosiale ondersteuning. Die resultate van hierdie studie brei uit op die huidige literatuur oor gesinsveerkragtigheid en kan gebruik word om families wat vir demensiepatiënte sorg te help om 'n familie-omgewing te skep wat die gesin se aanpasbaarheid verbeter. Die resultate kan ook gebruik word in die ontwikkeling en evaluering van intervensieprogramme wat die behoeftes van hierdie subgroepe teiken.

TABLE OF CONTENTS

	Page
Declaration.....	ii
Acknowledgements.....	iii
Summary.....	v
Opsomming.....	vi
Table of Contents.....	vii
List of Tables.....	xii
List of Figures.....	xiii
 1. INTRODUCTION, MOTIVATION, AND AIMS OF THE STUDY.....	 1
1.1 Introduction.....	1
1.2 Chapter Preview.....	1
1.3 Conceptualisation of the Constructs.....	2
1.3.1 Dementia.....	2
1.3.2 Family resilience.....	4
1.3.3 Family caregiving.....	5
1.4 Problem Statement and Motivation for the Study	5
1.5 Primary Aims and Objectives of the Study.....	9
1.6 Outline of the study.....	10
 2. FAMILY RESILIENCE.....	 12
2.1 Introduction.....	12
2.2 Resilience as a construct.....	12
2.3 Evolution of the Family Resiliency Model.....	15
2.3.1 Hill's ABCX Model.....	16
2.3.2 The Double ABCX Model.....	16

2.3.3	The Family Adjustment and Adaptation Response Model (FAAR).....	17
2.3.4	T-Double ABCX Model.....	18
2.3.5	Resiliency Model of Family Stress, Adjustment and Adaptation.....	18
2.4	Resiliency Model of Family Stress, Adjustment and Adaptation.....	19
2.4.1	Family adjustment phase.....	19
2.4.1.1	Balance and harmony.....	21
2.4.1.2	The stressor [A]	21
2.4.1.3	Family vulnerability [V]	22
2.4.1.4	Family typology of established patterns of functioning [T]	22
2.4.1.5	Family resistance resources [B]	22
2.4.1.6	Family appraisal of the stressor [C]	23
2.4.1.7	Family problem solving and coping [PSC]	23
2.4.1.8	Family bonadjustment, maladjustment, and crisis [X]	24
2.4.2	Family adaptation.....	24
2.4.2.1	Family adaptation [XX]	26
2.4.2.2	Pile-up [AA] of demands.....	26
2.4.2.3	Family types and newly instituted patterns of functioning [T&TT]	27
2.4.2.4	Family resources [BB]	28
2.4.2.5	Social support [BBB]	29
2.4.2.6	Family appraisal processes [C to CCCCC]	29
2.4.2.7	Family problem solving and coping [PSC]	32
2.5	Walsh's Family Resilience Framework.....	33

2.6	Motivation for Selecting the Theoretical Framework Used in the Present Study.....	35
2.7	Conclusion.....	37
3.	LITERATURE REVIEW.....	38
3.1	Introduction.....	38
3.2	The Impact of an Illness Stressor on the Family.....	39
3.3	Family Belief Systems.....	41
3.3.1	Making meaning of adversity	41
3.3.2	Positive outlook.....	47
3.3.3	Transcendence and spirituality.....	52
3.4	Family Organisational Patterns.....	54
3.4.1	Flexibility.....	54
3.4.2	Connectedness.....	56
3.4.3	Social support.....	60
3.4.4	Economic resources.....	65
3.5	Communication and Problem-solving Processes.....	66
3.6	Individual Characteristics of Family Members.....	69
3.7	Conclusion.....	70
4.	METHODOLOGY.....	72
4.1	Introduction.....	72
4.2	Research Design.....	72
4.3	Participants.....	73
4.3.1.	Sampling strategy and procedure.....	73
4.3.2.	Demographics of participants.....	75
4.4	Measures.....	77
4.4.1	Biographical questionnaire.....	77

4.4.2	Qualitative measure.....	77
4.4.3	Quantitative measuring instruments.....	78
4.4.3.1	Family Attachment Changeability Index 8 (FACI8)	78
4.4.3.2	Family Crisis Oriented Personal Evaluation Scales (F-COPES)	79
4.4.3.3	Family Hardiness Index (FHI)	80
4.4.3.4	Family Problem Solving and Communication (FPSC) Index	80
4.4.3.5	Family Time and Routine Index (FTRI)	81
4.4.3.6	Relative and Friend Support Index (RFS)	82
4.4.3.7	Social Support Index (SSI)	82
4.5	Procedure.....	83
4.6	Data Analysis.....	86
4.6.1	Quantitative data analysis.....	86
4.6.2	Qualitative data analysis.....	86
4.6.3	Trustworthiness.....	87
4.7	Ethical Considerations.....	88
5.	RESULTS.....	91
5.1	Introduction.....	91
5.2	Demographic Results.....	91
5.3	Quantitative data.....	93
5.3.1.	Analysis of variance (ANOVA)	93
5.3.2.	Pearson's product-moment correlations.....	97
5.3.3.	Multiple regression analyses.....	103
5.4	Qualitative Data.....	108

6.	DISCUSSION.....	117
6.1	Introduction.....	117
6.2	Stressor Event.....	117
6.3	Family Belief Systems.....	119
6.3.1	Making meaning of adversity.....	119
6.3.2	Positive outlook.....	122
6.3.3	Transcendence and spirituality.....	125
6.4	Family Organisational Patterns.....	127
6.4.1	Flexibility.....	127
6.4.2	Connectedness.....	129
6.4.3	Social support.....	132
6.4.4	Economic resources.....	137
6.5	Communication and Problem-solving Processes.....	139
6.6	Individual characteristics of family members.....	141
6.7	Conclusion.....	142
6.8	Limitations and Suggestions for Future Research.....	145
	REFERENCES.....	149
	ADDENDUMS.....	157
	Addendum A: Letter from Supervisor.....	157
	Addendum B: Agreement to help identify participants.....	158
	Addendum C: Flyers.....	162
	Addendum D: Contact details form.....	163
	Addendum E: Biographical Questionnaire.....	164
	Addendum F: Quantitative Questionnaires.....	170
	Addendum G: Consent form.....	186

LIST OF TABLES

Table 5.1 Spearman's Correlation Coefficients Found Between the Demographic Variables and the Level of Family Adaptation as Measured by the FACI8 (N = 91).....	92
Table 5.2 Pearson's Product-moment Correlations Found Between the Independent Variables and the Level of Family Adaptation as Measured by the FACI8 (N = 91)	98
Table 5.3 Multiple Regression Analysis: The Best Combination of Predictor Variables for Family Adaptation in the Spouse Subgroup (n = 44).....	103
Table 5.4 Multiple Regression Analysis: The Best Combination of Predictor Variables for Family Adaptation in the Child Subgroup (n = 47).....	105
Table 5.5 Resilience Resources as Identified by Spouses and Children (N = 40) in Qualitative Interview.....	109

LIST OF FIGURES

Figure 2.1 The adjustment phase of the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1996).....	20
Figure 2.2 The adaptation phase of the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1996).....	25
Figure 5.1 ANOVA: Results Obtained on the Total Score of the FACI8.....	93
Figure 5.2 ANOVA: Results Obtained on the Total Score of the SSI.....	94
Figure 5.3 ANOVA: Results Obtained on the Total Score of the FPSC.....	95
Figure 5.4 ANOVA: Results Obtained on the Affirming Communication Subscale of the FPSC.....	95
Figure 5.5 ANOVA: Results Obtained on the Incendiary Communication Subscale of the FPSC.....	96
Figure 5.6. ANOVA: Results Obtained on the Family Management Routines Subscale of the FTRI.....	97
Figure 5.7a Histogram comparing the results of the 20 best subsets of the regression analysis (Spouse-subgroup).....	106
Figure 5.7b Histogram comparing the results of the 20 best subsets of the regression analysis (Child-subgroup).....	107

CHAPTER 1

INTRODUCTION, MOTIVATION, AND AIMS OF THE STUDY

1.1 Introduction

Dementia is a chronic illness characterised by the progressive deterioration of cognitive functions. It is a worldwide phenomenon that afflicts one in 20 people over the age of 65 and one in five people over the age of 80 (Dementia South Africa, 2010). Even though dementia is not a normal part of ageing, age is a key risk factor in the development of this illness. Due to population ageing, it thus can be expected that the number of individuals with dementia will increase dramatically in the coming years. Research shows that the number of patients diagnosed with dementia worldwide will reach an estimated 81.1 million by 2040 (Dementia South Africa, 2010).

Dementia patients are most often cared for by family members (Ablitt, Jones & Muers, 2009; Chiou, Chang, Chen & Wang, 2009; Mitrani & Czaja, 2000; Pattanayak, Jena, Tripathi & Khandelwal, 2010; Schoenmakers, Buntinx & DeLepeleire, 2010; Weitzman, Neal, Chen & Levkoff, 2008; Zarit, 2008). Dementia, often dubbed “*the disease of the family*”, is an illness that has a significant effect on the families of the individuals afflicted – especially on those taking on the role of caregiver (Albinsson & Strang, 2003; Goldsteen et al., 2007). However, some families show resilience and are able to overcome the adversity of the illness. What factors help these families to adapt to their situation and counteract the difficulties that impair family functioning? This study aims to answer this question by exploring resilience factors these families utilise to rise above the hardships faced when caring for a family member diagnosed with dementia.

1.2 Chapter Preview

This chapter acts as an introduction to the present study and opens with the definitions of a few relevant constructs. This is followed by a discussion of the problem statement and motivation for the study, which focuses predominantly on the various ways in which caring for a family member diagnosed with dementia may affect the functioning of the family unit. In addition, the chapter describes the aims

and objectives of the study and concludes with a summary of the subsequent chapters.

1.3 Conceptualisation of the Constructs

1.3.1 Dementia

Dementia is a chronic illness that progressively impairs the cognitive functions of the patient. One of the most prominent symptoms of dementia is memory impairment. Memory impairment is usually mild in the early stages of dementia, but, as the illness progresses, the memory of the patient gradually deteriorates until only the earliest learned information is retained (e.g. the patient's place of birth). Other general symptoms present in dementia patients include poor impulse control; mood disturbances (e.g. irritability, depression); noticeable personality changes; and behavioural disturbances (e.g. wandering, agitation, violent behaviour). Dementia also impairs the patient's ability to reason logically, solve problems, and make sound judgments. Hallucinations and delusions are also prominent in some dementia patients (Sadock & Sadock, 2007).

Because dementia is a universal illness that has many causes, the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) differentiates between six diagnoses of dementia: (1) *Dementia of the Alzheimer's type*; (2) *Vascular dementia*; (3) *Dementia due to other general medical conditions*; (4) *Substance-induced persisting dementia*; (5) *Dementia due to multiple etiologies*; and (6) *Dementia not otherwise specified* (Sadock & Sadock, 2007). However, all dementia types have certain symptoms in common. The DSM-IV-TR stipulates that all dementia patients develop multiple cognitive deficits during their illness that severely impairs their occupational or social functioning. Such cognitive deficits must represent a significant decline from a previous level of functioning and should manifest in both memory impairment and other symptoms of cognitive decline. The DSM-IV-TR specifies that patients must show at least one of the following cognitive impairments: (a) language disturbance (aphasia); (b) impaired motor activities (apraxia); (c) impaired ability to identify or recognise objects, faces or other sensory information (agnosia); and (d) disturbances in executive functioning (e.g. planning, organising, abstract thinking) (Sadock & Sadock, 2007).

Dementia of the Alzheimer's type is the most common cause of dementia in individuals over the age of 65 (Feldman et al., 2008; Liebson, Rauch, Graff & Folstein, 2005; Sadock & Sadock, 2007). Although the true cause of this disorder is unknown, it is believed that genetic traits contribute to the development of Alzheimer's disease. A diagnosis of dementia of the Alzheimer's type, as specified in the DSM-IV-TR, requires that the general criteria for dementia are met and cannot be explained by any other cause of dementia. The diagnostic criteria also emphasise a gradual and continuous decline in the patient's functioning. The final diagnosis of Alzheimer's disease can only be determined via a neuropathological inspection of the brain (Sadock & Sadock, 2007).

Vascular dementia is the second most common cause of dementia (Feldman et al., 2008; Liebson et al., 2005; Sadock & Sadock, 2007) and is caused primarily by cerebral vascular disease. The diagnostic criteria of vascular dementia consists of the same general dementia symptoms as Alzheimer's disease, but also requires clinical or laboratory evidence supporting a vascular cause. Individuals with vascular dementia may also experience additional neurological symptoms, like dizziness, headaches, weakness and sleep disturbances (Sadock & Sadock, 2007).

If a patient meets the general criteria of dementia, but evidence from a physical examination, laboratory findings or patient history indicate that the symptoms are caused directly by a general medical condition other than cerebrovascular disease or Alzheimer's disease, the DSM-IV-TR classifies it as *Dementia due to other general medical conditions*. The DSM-IV-TR identifies six causes of dementia that can be coded directly: (1) the human immunodeficiency virus (HIV); (2) Creutzfeldt-Jakob disease; (3) Huntington's disease; (4) Parkinson's disease; (5) Pick's disease; and (6) head trauma. Other medical causes of dementia – like normal pressure hydrocephalus (NPH); syphilis; hypothyroidism; brain tumours; or vitamin B₁₂ deficiency – can be coded under a seventh category labelled "*Other*" (Sadock & Sadock, 2007).

The diagnostic criteria of substance-induced persisting dementia, as identified in the DSM-IV-TR, require that the patient meets the criteria for dementia, and that the patient history, laboratory results or a physical examination show that these

symptoms are etiologically connected to the continuous effect of substance use (e.g. alcohol, anxiolytics, hypnotics, inhalants or sedatives). Clinicians have to ensure that the deficits experienced by the patient are not due to normal substance intoxication or withdrawal (Sadock & Sadock, 2007).

Dementia symptoms with several causes (e.g. mixed vascular and Alzheimer's dementia) are classified as *Dementia due to multiple etiologies* by the DSM-IV-TR. If no criteria of any of the specific types of dementia identified in the DSM-IV-TR are met, it is classified as *Dementia not otherwise specified* (Sadock & Sadock, 2007).

1.3.2 Family resilience

The construct that explains how families overcome adversity and do well, even when faced with significant stressors, is known as family resilience (Patterson, 2002a, 2002b; Walsh, 2002, 2003). McCubbin and McCubbin (1996) defined family resilience as:

...the positive behavioural patterns and functional competence individuals and the family unit demonstrate under stressful or adverse circumstances, which determine the family's ability to recover by maintaining its integrity as a unit while insuring, and where necessary restoring, the well-being of family members and the family unit as a whole (p. 5).

This study used a combination of McCubbin and McCubbin's (1996) Resiliency Model of Family Stress, Adjustment and Adaptation and Walsh's (2002, 2003) Family Resilience Framework as a theoretical framework to identify and explore factors that are associated with the ability of families caring for a family member diagnosed with dementia to adjust and adapt to their situation. A more in-depth discussion of family resilience as a construct and an outline of the theoretical framework used in this study are presented in Chapter 2.

1.3.3 Family caregiving

The American Heritage Dictionary of the English Language (2009) defines a caregiver as “an individual [...] who attends to the needs of a child or dependent adult”. However, caregiving is a complex, multidimensional concept that includes both direct tasks (e.g. hygienic care; meal preparation; health care; transportation; shopping) and indirect tasks (e.g. financial management; delegation and management of activities; institutionalisation of the patient) (Swanson et al., 1997). The growing cost of health care and changing demographic patterns have shifted the responsibility of direct care from institutions to informal caregivers (Swanson et al., 1997). In most cases, family members – especially the spouses or adult children of patients – step in as caregivers (Ablitt et al., 2009; Chiou et al., 2009; Haley et al., 1996; Mitrani & Czaja, 2000; Pattanayak et al., 2010; Schoenmakers et al., 2010; Schulz & Martire, 2004; Swanson et al., 1997; Weitzman et al., 2008; Zarit, 2008).

The current study defines family as two or more individuals living in the same household who are connected through blood, marriage or a domestic partnership, or adoption (Nam, 2004). This study focused on families in which the spouse or adult children of the dementia patients took on the role of primary caregivers, caring directly for the dementia patient.

1.4 Problem Statement and Motivation for the Study

South Africa is burdened with limited health-care resources. The health-care system is often unsuitable for managing patients with long-term or terminal diseases (like dementia) due to the high cost of institutional care; a shortage of health professionals in the public sector; over-crowded hospitals; and a lack of treatment resources (Department of Health, 2001). As a result, patient care usually falls upon family members (Ablitt et al., 2009; Chiou et al., 2009; Haley et al., 1996; Swanson et al., 1997; Mitrani & Czaja, 2000; Pattanayak et al., 2010; Schoenmakers et al., 2010; Weitzman et al., 2008; Zarit, 2008). Due to higher life expectancy, a dramatic increase in the prevalence of dementia is expected in the coming decades (Ablitt et al., 2009; Davis, 1997; Sadock & Sadock, 2007). The importance of family-based dementia care is thus likely to continue to increase (Ablitt et al., 2009; Zarit, Femia, Kim & Whitlatch, 2010).

Many families prefer caring for their terminally ill family members at home (Weitzman et al., 2008; Zarit, 2008). However, families caring for a dementia patient are faced with tasks that are physically exhausting and psychologically distressing (Schulz & Martire, 2004). Dementia patients are completely dependent on their caregivers for simple activities of daily living, like dressing, bathing and toileting (Au et al., 2009; Gilliam & Steffen, 2006; Goldsteen et al., 2007; Gottlieb & Wolfe, 2002; Pattanayak et al., 2010; Schulz & Martire, 2004; Zarit et al., 2010). Dementia caregivers are also responsible for managing the healthcare of the patient, like getting the dementia patient to appointments with a physician or the administration of prescribed medication (Au et al., 2009; Schulz & Martire, 2004). In addition to having to adjust to the increasing dependency of the dementia patient, family members have to take over the roles previously carried out by the dementia patient (Goldsteen et al., 2007; Quinn, Clare, Pearce & Van Dijkhuizen, 2008).

The increase in responsibilities brought about by taking on the role of caregiver often leaves family members with a reduction in their leisure time (Zarit et al., 2010). They often give up activities of interest and increasingly stay at home, which could lead to social isolation (Albinsson & Strang, 2003; Au et al., 2009; Bormann et al., 2009; Haley, Levine, Brown & Bartolucci, 1987; Herrmann & Gauthier, 2008; Mitrani & Czaja, 2000; Pattanayak et al., 2010; Quinn et al., 2008). Working caregivers also report that caregiving often interferes with their work. Job-related difficulties caused by caregiving responsibilities (e.g. working fewer hours; being overly tired at work; taking unpaid leave of absence; and missing new job opportunities) could place an economic burden on the family (Albinsson & Strang, 2003; Chang, 2009; Chiou et al., 2009; Herrmann & Gauthier, 2008; Pattanayak et al., 2010; Schulz & Martire, 2004; Zarit, 2008; Zarit et al., 2010).

Family members taking care of a loved one diagnosed with dementia are also faced with a severe emotional burden. They witness how the mental functioning of a person they love progressively declines due to an illness that currently has little hope of cure. Dementia patients gradually withdraw into their own world, causing declines in communication, reciprocity, and opportunities for shared activities. Their identities fade as the illness progresses and their loved ones eventually become strangers to them. As a result, the relationships the family members use to have with the patient

cease to exist (Ablitt et al., 2009; Davis, 1997; Goldsteen et al., 2007; Quinn et al., 2008; Sadock & Sadock, 2007; Schulz & Martire, 2004). In addition, families caring for dementia patients also face embarrassment caused by the patient's behavioural problems, like the neglect of personal appearance and hygiene, the use of coarse language, and general hostility. Due to their lack of judgment and poor impulse control, dementia patients often show a disregard for the conventional rules of social conduct and the effects of their behaviour on others (Au et al., 2009; Davis, 1997; Gottlieb & Wolfe, 2002; Haley et al., 1987; Pattanayak et al., 2010; Sadock & Sadock, 2007; Zarit, 2008; Zarit et al., 2010). Adapting to these cognitive, behavioural and personality changes could be challenging, and family caregivers sometimes lose patience, get angry, or even gradually develop resentment towards the patient (Bormann et al., 2009; Lopez, Lopez-Arrieta & Crespo, 2005; Pattanayak et al., 2010; Quinn et al., 2008; Sadock & Sadock, 2007; Zarit, 2008; Zarit et al., 2010). These family members usually struggle with feelings of loss, grief, and guilt due to the deterioration of their relationship with the patient (Davis, 1997; Sadock & Sadock, 2007; Schulz & Martire, 2004; Zarit et al., 2010).

Intra-family relations between healthy family members are also severely affected by dementia. Caregivers often blame themselves or other family members for the patients' indiscretions – or even their illness (Sadock & Sadock, 2007). Conflict between family members can also arise due to disagreements regarding the division of responsibilities or the implementation of caregiving tasks. Consequently, the relationship quality between these family members often decreases as well (Gottlieb & Wolfe, 2002; Schulz & Martire, 2004; Zarit et al., 2010).

Studies suggest that the demanding nature of dementia care and the prolonged psychological distress that these families face could affect the physiological functioning of family members caring for the dementia patient and increase their risk for physical health problems. Research has shown that dementia caretakers often show reduced immune responses, changes in hormonal levels, higher levels of insulin production, higher blood pressure and higher heart rates compared to non-caregiving controls. These individuals also showed lower self-rated health behaviours, like healthy eating habits, getting enough rest, regular exercise, and taking care of their own health problems. Furthermore, these individuals are at risk of

developing mental health problems, like anxiety and depression (Albinsson & Strang, 2003; Au et al., 2009; Bormann et al., 2009; Chang, 2009; Chiou et al., 2009; Gilliam & Steffen, 2006; Haley et al., 1987; Herrmann & Gauthier, 2008; Heru & Ryan, 2006; Lopez et al., 2005; Majerovitz, 1995; Marquez-Gonzalez, Losada, Izal, Pérez-Rojo & Montorio, 2007; Mitrani & Czaja, 2000; Pattanayak et al., 2010; Quinn et al., 2008; Roth, Haley, Owen, Clay & Goode, 2001; Schulz & Martire, 2004; Weitzman et al., 2008; Zarit, 2008; Zarit & Femia, 2008; Zarit et al., 2010).

Even though most families endure great stress when caring for a family member suffering from dementia, some are more susceptible to psychosocial impairment than others (Ablitt et al., 2009; Gilliam & Steffen, 2006; Haley et al., 1987). When families are unable to deal with the problems of dementia homecare, it significantly reduces family functioning (Davis, 1997; Roth et al., 2001). Furthermore, studies show that the well-being of the caregiver has a significant effect on the well-being of the dementia patient, and that caregivers who are well supported provide a better quality of dementia care (Ablitt et al., 2009; Roth et al., 2001). Given the projected increase in the prevalence of dementia, and the fact that most dementia patients receive homecare by family members, there is a need for intervention strategies that help families cope with the demands of dementia care. However, empirical evidence on effective intervention strategies that help family members cope with the challenges of caring for a dementia patient is limited (Bormann et al., 2009; Marquez-Gonzalez et al., 2007; Mitrani & Czaja, 2000; Schoenmakers et al., 2010; Zarit & Femia, 2008).

Understanding the factors that help families to cope with the negative aspects of dementia care is essential in the development of successful family-based intervention strategies (Gilliam & Steffen, 2006). The question thus arises: What are the primary family characteristics and support structures that help families overcome the difficulties of caring for a family member diagnosed with dementia? A contextual framework for this question is provided in the family resilience paradigm, which can be used to find the much-needed answers to this question. Family resilience contributes to family well-being and counteracts difficulties that impair family functioning (Heru & Ryan, 2006). More resilient families are usually more accepting of the changes in the behaviour of the dementia patient; better prepared for the

inevitable role changes and changes in their own lives brought about by the illness; more open to the development of new coping strategies in response to the demands of dementia care; and experience better psychological adjustment (Majerovitz, 1995). Exploring the resilience factors that families possess and utilise to deal with the demands of caregiving could thus provide useful strategies that can be incorporated into the development and testing of interventions directed at easing the transitions families face when a family member is diagnosed with dementia.

Several studies have focused on resilience in families caring for a family member suffering from a chronic illness (Bester, 2009; Greeff & Thiel, 2012; Greeff, Van Steenwegen & Ide, 2006; Greeff & Wentworth, 2009; Jonker & Greeff, 2009). However, none of the literature that could be found on family resilience focused on dementia care. Each chronic illness has a unique set of stressors that the families caring for the patient have to deal with, which could influence the resilience of the family (Albinsson & Strang, 2003; Hawley, 2000; Zarit et al., 2010). The findings of these studies thus should not be generalised to families caring for dementia patients. Taking all of these aspects into consideration, it was deemed necessary to explore resilience factors in families caring for a family member diagnosed with dementia.

1.5 Primary Aims and Objectives of the Study

The primary aim of this study was to identify, explore and describe resilience factors that were present in families caring for a family member diagnosed with dementia. A mixed methods approach was followed to collect data from a convenience sample drawn from the Cape Metropolitan area. The study focused specifically on spouses and adult children caring for the dementia patient. The family resilience factors of these family subgroups were explored separately and were compared with each other to determine whether any significant differences were evident regarding the prevalence of resilience factors in the families of these two groups.

This study seeks to provide a body of information that contributes to the current literature regarding family resilience. In addition, the study seeks to encourage further examination on a larger scale of family resilience in families caring for a dementia patient, specifically in the South African context. These future empirical

studies can be used in the development and evaluation of intervention programmes targeting South African families caring for a family member diagnosed with dementia.

1.6 Outline of the Study

The thesis will be presented as follows: in Chapter 2, the development of the theoretical framework underlying the present study is discussed. Firstly, resilience is defined and the development of family resilience is discussed as a construct. This is followed by an outline of the evolution of the family resilience framework used in the present study – the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1996). Furthermore, there is a discussion of Walsh's (2002, 2003) Family Resilience Framework, which also forms part of the theoretical basis of the current study. In conclusion, the chapter motivates why the chosen theoretical framework was considered the most suitable choice for this study.

Chapter 3 provides a literature review on family resilience in families caring for a member suffering from a chronic illness. Since none of the family resilience studies found focused on dementia patients specifically, the chapter also examines individual resilience in family caregivers coping with the burden of dementia care. The chapter concludes with a discussion of the relevance of these findings in terms of the South African context, the family resilience paradigm, and the dementia perspective.

Chapter 4 elaborates on the methodology used to study the resilience factors present in families caring for a family member diagnosed with dementia. In this chapter, the research question is formulated, the primary aim of the study is stated, and the methods used to gather data (which includes the research design, sampling procedures, data collection measures, research procedures and data analyses) are discussed. The chapter concludes with an outline of the ethical considerations of the study.

Chapter 5 presents the qualitative and quantitative findings of the present study.

In Chapter 6, the findings that were presented in Chapter 5 will be integrated into the theoretical framework used in this study, and will be compared with previous

research. The conclusions that were drawn based on these results will also be discussed. This will be followed by a discussion of the limitations of this study and the provision of recommendations for future research.

CHAPTER 2

FAMILY RESILIENCE

2.1 Introduction

In the past, the emphasis of family research was mainly on pathology and family deficits. Recently, however, this emphasis has shifted to the strengths and resources of families that help them to overcome difficult life events. Researchers want to know why some families are able to withstand and rebound from adversity, while others deteriorate under the same circumstances. The construct that explains how families overcome adversity and do well, even when faced with significant stressors, is known as family resilience (Patterson, 2002a, 2002b; Walsh, 2002, 2003). McCubbin and McCubbin's (1996) Resiliency Model of Family Stress, Adjustment, and Adaptation and Walsh's (2002, 2003) Family Resilience Framework provide the theoretical foundation of the current study. This chapter will provide a summary of the evolution of the Resiliency Model, followed by an outline of the family Resiliency Models used as the theoretical framework for this study. Furthermore, this chapter will explore the relevance of these models in the South African context. Before elaborating on these models, however, the chapter will discuss the development of family resilience as a construct.

2.2 Resilience as a Construct

In the past, psychological research focused primarily on adaptive deficits and problems in individuals facing adverse circumstances. However, as the research field expanded, ever-increasing evidence showed that identical stressors were often experienced differently by different individuals. Although some individuals exposed to high-risk circumstances suffer negative outcomes, many overcome their deprived environments and are able to thrive and lead loving, productive lives (Black & Lobo, 2008; Hawley & DeHaan, 1996; Walsh, 2002, 2003). Researchers were curious about why some individuals are able to cope when faced with hardship, while others fall apart. As a result, the mental health theory underwent a shift in emphasis and adopted a salutogenic approach. Instead of focusing on deficits, the salutogenic approach emphasises the factors that contribute to the health and well-being of individuals faced with adverse conditions. The salutogenic approach offers a strong

framework for conceptualising resilience (Lavee, McCubbin & Olson, 1987; Patterson, 2002a, 2002b).

Walsh (2003) defines resilience as “the ability to withstand and rebound from crisis and adversity” (p. 1) and describes it as a dynamic process concerning positive adaptation, which enables individuals to respond effectively to crisis situations and to recover and grow from the experiences encountered when faced with adversity. Hawley and DeHaan (1996) depict resilience as a process that helps families “adapt to stress and bounce back from adversity” (p. 283). Grafton, Gillespie and Henderson (2010) define resilience as the ability to manage the negative impact of stress effectively and to transform it into a positive learning experience, thus sustaining physical, psychological and spiritual well-being and reducing vulnerability to future stressors.

Resilience was initially perceived as an innate characteristic that resilient persons were either born with – “biological hardiness” – or acquired themselves through their own personal resourcefulness or good luck. Earlier studies focused mostly on the personal strengths and inner fortitude of individuals who thrived in spite of destructive family environments. These individuals – often described as the “invulnerable child” – were viewed as impervious to stress due to their “character armour”, thus mirroring the myth of the “rugged individual” that was imbedded in the dominant ethos of the time (Walsh, 1996, 2002, 2003).

As the knowledge base on resilience expanded, researchers started recognising the significance of the interaction between nature and nurture in the resilience paradigm. However, the views researchers had on family influences were still deficit based and pessimistic, which blinded them to family strengths. It thus was believed that families contributed to risk, but not to resilience. Researchers tended to dismiss the family as hopelessly dysfunctional and rather searched for extra-familial sources of resilience to counter the negative influence of the seemingly noxious family (Walsh, 1996, 2002, 2003).

Researchers started expanding research on resilience to a wider range of adverse conditions. Studies found that troubled children or teens still had the potential to

develop resilience later in life, thus suggesting that the vulnerability of an individual could be outweighed by mediating influences. Researchers found that resilience involved a relationship between several risk and protective processes over time, and increasingly noted the role both family and larger socio-cultural factors played in the resilience process. Families were thus deemed either a protective factor or a risk factor in individual resilience – the individual still acting as the unit of analysis (Hawley, 2000; Hawley & DeHaan, 1996; Walsh, 2002, 2003).

Research showed that crises affect the whole family and could disrupt the functioning of the family system, which in turn influences all the family members and their relationships. Conversely, when faced with crises, family processes could mediate the recovery of the family unit and all its members, which enables the family system to unite, buffers the family against stress, reduces the risk of dysfunction, and ultimately supports optimal adaptation. As a result, researchers started showing support for the notion that resilience could be deemed a family-level construct, as opposed to restricting it to a resource for individual resilience (Hawley, 2000; Hawley & DeHaan, 1996; Patterson, 2002a; Walsh, 2003).

There are various definitions of family resilience. McCubbin and McCubbin (1988) depicted family resilience as “characteristics, dimensions, and properties of families which help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations” (p. 247). Walsh (1996) defined family resilience as “key processes that enable families to cope more effectively and emerge harder from crises or persistent stresses, whether from within or from outside the family” (p. 263). Family resilience has also been described as: “the path a family follows as it adapts and prospers in the face of stress, both in the present and over time” (Hawley & DeHaan, 1996, p. 293); “the strength that supports family functioning as changes and adaptations are required in the family in response to both internal and external forces” (Lee et al., 2004, p. 644); and “the successful coping of families during life transitions, stress, or adversity” (Black & Lobo, 2008, p. 33). McCubbin and McCubbin (1996) posed the following definition for understanding family resilience as it is utilised in this study:

[Family] resilience can be defined as the positive behavioural patterns and functional competence individuals and the family unit demonstrate under stressful or adverse circumstances, which determine the family's ability to recover by maintaining its integrity as a unit while insuring, and where necessary restoring, the well-being of family members and the family unit as a whole (p. 5).

These definitions emphasise several important characteristics of family resilience. Firstly, resilience surfaces in the face of hardship and cannot exist without struggle. At some point, all families will face problems and resilience entails the families' responses to these difficulties. Resilience is characterised by a family's ability to maintain healthy family functioning, regardless of the hardships they face. Secondly, resilience is characterised by buoyancy. Even if families struggle temporarily under stressful conditions, resilient families are able to "bounce back" by invoking recovery factors that promote their ability to adapt. Resilient families sometimes experience growth due to the challenges they have faced, thus helping them to not only rebound from a crisis, but also to surpass their pre-crisis level of functioning and emerge more competent in dealing with future problems (Black & Lobo, 2008; Hawley, 2000; Hawley & DeHaan, 1996; Lee et al., 2004). Finally, resilience is generally defined in terms of wellness rather than pathology. Rather than focusing on family deficits, resilience emphasises the strengths and resources families utilise to overcome adversity (Hawley, 2000; Hawley & DeHaan, 1996).

In the quest to better understand the family resilience process, several researchers have made significant contributions to ensure the growth of the family resilience paradigm. McCubbin and McCubbin's (1996) Resiliency Model of Family Stress, Adjustment, and Adaptation, and Walsh's (2002, 2003) Family Resilience Framework, have been particularly noteworthy in this regard and have provided the theoretical foundation for the current study. However, before providing a detailed description of these models, the evolution of these theories will be discussed.

2.3 Evolution of the Family Resiliency Model

Family resilience theory was developed in an attempt to understand why some families are able to cope with adversity, while others deteriorate when they face

similar or even identical hardships. Research expanding on family resilience theory revealed limitations to earlier family resilience frameworks. These findings motivated the subsequent evolution of the Family Resiliency Model to its current form – the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1996). The following section discusses the development and evolution of the family resilience framework.

2.3.1 Hill's ABCX Model

In 1949, Reuben Hill formulated a family Resiliency Model, known as the ABCX Model, explaining how stressors affected families. According to the ABCX Model, a stressor event [A] interacts with the crisis-meeting resources available to the family unit [B] and the family's definition of the stressor event [C] to produce a crisis [X]. Hill's ABCX Model contributed to the field of family stress and family resilience by challenging the linear and deterministic view that stressors caused crises. The model introduced two sets of mediating variables (resources and definitions) that empower families to overcome stressor events over which they have no direct control, thus avoiding a state of crisis. This model provided a foundation for later research on family strengths, thus facilitating the development of later models (Van Breda, 2001).

2.3.2 The Double ABCX Model

The Double ABCX Model was developed by McCubbin and Patterson and improved on Hill's ABCX Model by redefining pre-crisis variables and adding four post-crisis variables to the model (McCubbin & McCubbin, 1996).

Firstly, McCubbin and Patterson theorised that families hardly ever face a single stressor. In addition to the crisis situation, families have to deal with a pile up of co-occurring stressors, prior hardship, and other strains over time. While the ABCX Model focused only on the single stressor preceding the crisis, the Double ABCX Model considered the collective effect of both past and future family strains. The model introduced the AA factor, which represents both the initial stressor and the pile up of co-occurring normative and non-normative strains (Lavee, McCubbin & Patterson, 1985; McCubbin & McCubbin, 1996).

Secondly, the Double ABCX Model pointed out that families are not restricted to one resource, but that they have multiple resources available to them. In addition, resources can change over time and could even be created when the family is faced with a crisis situation. As a result, the BB factor was integrated into the model to reflect both the families' existing resources and the resources that were developed and strengthened by them in response to the crisis situation (Lavee et al., 1985; McCubbin & McCubbin, 1996). Family resources include (1) personal resources, like the characteristics, knowledge and skills of individual family members; (2) family system resources, such as adaptability, cohesion and communication; and (3) social support (Lavee et al., 1985).

The CC factor, defined as the family's perception of the total crisis situation, is the third variable added in the Double ABCX Model. Family appraisal is a more complex process than a simple definition of the stressor and its severity. The appraisal process involves the continuous assessment of the total situation, which includes the demands placed by the stressor, the capabilities of the family and the available family resources (Lavee et al., 1985; McCubbin & McCubbin, 1996).

Finally, family crises do not typically lead to family dysfunction. Most families are able to adapt to stressful situations. Families respond to these situations by adjusting their coping behaviour or changing their established strategies and patterns of functioning. In response to these findings, the XX factor – defined as the family outcomes following a crisis situation – was introduced in the Double ABCX Model. The family outcomes [XX] were described as a continuum of family adaptation that ranged from maladaptation at the negative end of the continuum, to bonadaptation at the positive end of the continuum (Lavee et al., 1985; McCubbin & McCubbin, 1996).

2.3.3 The Family Adjustment and Adaptation Response Model (FAAR)

Adapting to a crisis situation is not a fixed event, but entails complex processes in which the family's functioning changes. In response to this, McCubbin and Patterson developed the Family Adjustment and Adaptation Response Model (FAAR). The FAAR Model introduced the *resistance* phase, the *restructuring* phase and the *consolidation* phase into the family stress model and established a distinction between the *adaptive* and *adjustment* coping strategies (McCubbin & McCubbin,

1996). Family adjustment refers to a family's short-term response to a crisis and is usually only sufficient to deal with less severe stressors. Families are usually reluctant to make changes or adjustments to established patterns of family functioning when first exposed to a stressor. Families initially respond to these stressors through avoidance (denying or ignoring the stressor); elimination (removing the demands of the stressor); or assimilation (accepting the demands of the stressor). If a family is unable to cope with the demands of the stressor and is not able to avoid or remove those demands, it usually leads to maladjustment, which instigates a family crisis. The family crisis amplifies the family's need for change, which marks the beginning of the family adaptation stage. Adaptation is a long-term reaction that involves the reorganisation of family systems in an attempt to balance resources and demands when faced with a more severe crisis situation. Families alter their appraisals, capabilities, resources and coping strategies and make the necessary changes to ensure a member-to-family and family-to-community balance (McCubbin & McCubbin, 1996).

2.3.4 T-Double ABCX Model

McCubbin and McCubbin's T-Double ABCX Model, also known as the Typology Model of Family Adjustment and Adaptation, was developed to highlight the importance of a family's established patterns of functioning and levels of appraisal when adapting to a crisis situation. In accordance with the FAAR Model, the T-Double ABCX Model describes family coping in terms of adjustment and adaptation, but improves on the model by introducing *family typologies* [T] as a buffering factor against family dysfunction. In addition, *vulnerabilities* (V) due to pile up were introduced as a factor in both the adjustment and adaptation phases of the model. The model included *family schema* – defined as the shared views, beliefs and values of a family – as an additional level of family appraisal (CCC). Furthermore, the model acknowledged the importance of a family's life cycle stage in the adjustment and adaptation process (McCubbin & McCubbin, 1996).

2.3.5 Resiliency Model of Family Stress, Adjustment and Adaptation

McCubbin and McCubbin's (1996) Resiliency Model of Family Stress, Adjustment, and Adaptation (from here on referred to as the Resiliency Model) is the latest

addition to the family resilience framework. The Resiliency Model introduces *harmony* and *balance* as important family processes and goals – especially when families face adversity. The model integrates *family coping* and *problem solving* into the family resilience framework and accentuates the centrality of the relational processes of adjustment and adaptation in the family. In addition, it includes the family's established and instituted patterns of functioning as components of adjustment and adaptation. Furthermore, the model emphasises four major domains of family functioning (*Interpersonal relationships; Development, well-being and spirituality; Community relationships; and Structure and function*) and five important levels of family appraisal (*Schema; Coherence; Paradigms; Situational appraisal; and Stressor appraisal*) that are vital in family recovery. It also highlights the importance of culture and ethnicity, which were overlooked in earlier models (McCubbin & McCubbin, 1996). The Resiliency Model will be discussed in detail in the following section.

2.4 Resiliency Model of Family Stress, Adjustment and Adaptation

2.4.1 Family adjustment phase

During the adjustment phase (see Figure 2.1), the family makes relatively minor adjustments in an attempt to manage the demands of everyday strains, without severely disrupting their traditional patterns of functioning. The extent to which the family would adjust is influenced by several interacting components (McCubbin & McCubbin, 1996).

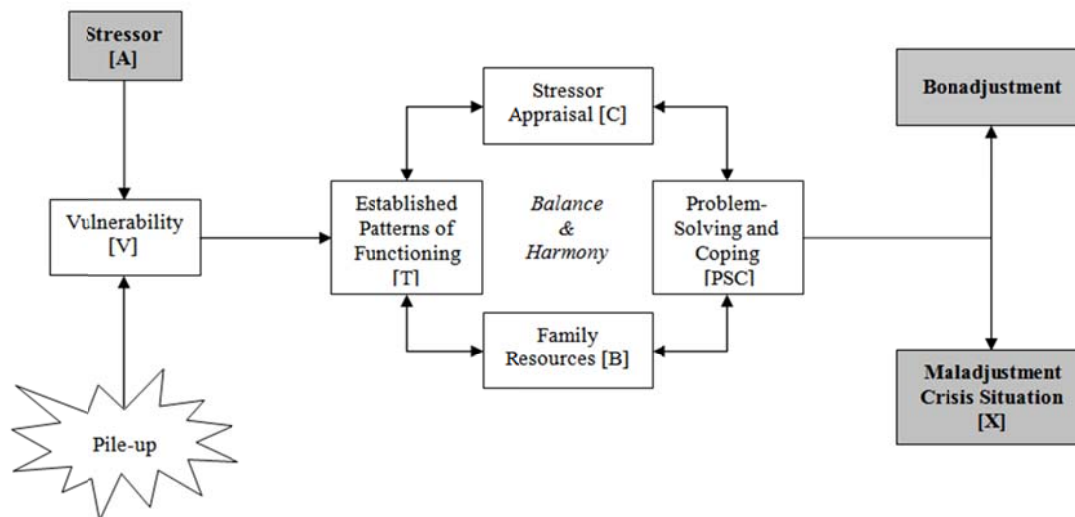


Figure 2.1 The adjustment phase of the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1996).

A stressor [A] interacts with the family's vulnerability [V], which is determined by the pile up of transitions, stresses and strains that the family has to deal with during that time. This vulnerability [V] interacts with the family's established patterns of functioning [T]. These components then interact with the resistance resources [B] that families use to maintain harmony and balance in the family system, which in turn interact with the family's appraisal of the stressor [C]. These two factors also interact with the family's problem-solving and coping strategies [PSC] (McCubbin & McCubbin, 1996).

The level of adjustment achieved is thus determined by the family's welfare at the onset of the stressor; the severity of the stressor event; the family's appraisal of the stressor; and the family resources and problem-solving and coping strategies utilised in an attempt to deal with the impact of the stressor. If the family views the stressor as manageable, and if the family's resistance resources and problem-solving and coping strategies are adequate, a state of bonadjustment will develop. However, if the stressor is too severe, a state of maladjustment develops. Families are then faced with a family crisis [X] that demands substantial changes in the family's typology to regain balance and harmony in the family system (McCubbin & McCubbin, 1996). Each component involved in the adjustment phase will now be discussed.

2.4.1.1 Balance and harmony

Families continuously pursue a general state of well-being, which is typically characterised by the presence of vitality and energy. When faced with a stressful event, families assume a state of imbalance and disharmony, thus necessitating adjustments in the family's practices in an attempt to restore the family to its former level of functioning. Four domains of family functioning are significantly affected by stressors, viz. the family's interpersonal relationships; the structure and function of the family; the well-being, development and spirituality of all family members; and the family's relationships and interaction with the surrounding community and their environment. These domains become the main focus points in the quest to restore and maintain harmony and balance within the family unit (McCubbin & McCubbin, 1996).

2.4.1.2 The stressor [A]

Stressors are challenges that alter, or have the potential to alter, family systems. Stressor events are generally characterised by imbalance and disharmony. The severity of a stressor is determined by the extent to which it disrupts family functioning, threatens the stability of the family system, and drains the family's resources (McCubbin & McCubbin, 1996). Research on family development distinguishes between two categories of stressors: normative and non-normative stressors. Normative stressors are the expected stressors families have to deal with over their life span, e.g. the transition to parenthood or launching a young adult into the world. These stressors are usually not viewed as a significant risk factor in families and most families are able to manage them effectively. However, they can set a risk process in motion if the timing of the change does not correspond with societal expectations, or if it triggers additional risks. In contrast, non-normative stressors are unanticipated (and often traumatic) events (e.g. illness), which often lead to significant risk. The unexpected nature of the event leaves the family with fewer guidelines to direct their response (Lavee et al., 1987; Patterson, 2002a, 2002b).

2.4.1.3 Family vulnerability [V]

Family vulnerability is described as “the interpersonal and organizational condition of the family system” (McCubbin & McCubbin, 1996, p. 17), which signifies the family’s susceptibility to a specific stressor. The vulnerability of a family can range from low to high and is influenced by the pile up of demands the family unit has to deal with (McCubbin & McCubbin, 1996). Family demands consist of (a) normative stressors; (b) non-normative stressors; (c) unresolved family tension; and (d) minor daily hassles (Patterson, 2002b).

2.4.1.4 Family typology of established patterns of functioning [T]

Family typology (T) is the family’s characteristics and typical behavioural patterns that predict how the family system typically operates and functions. The family’s established patterns of functioning plays a significant role in the development, reinstatement and maintenance of harmony and balance in the family unit (McCubbin & McCubbin, 1996).

2.4.1.5 Family resistance resources [B]

McCubbin and McCubbin (1996) define *family resistance resources* as:

...a family’s ability and capabilities to address and manage the stressor and its demands and to maintain and promote harmony and balance in an effort to avoid a crisis, or disharmony and imbalance, and substantial changes in or deterioration in the family’s established patterns of functioning (p. 19).

Families use psychosocial resources (family attributes and relationships); tangible resources (family possessions); and coping behaviours to help them deal with stressful events. These resources can be individual, family or community based (Patterson, 2002b). Resistance resources promote family resilience by buffering the family against the demands that arise from a stressor event. These resources play a vital role in preventing a stressor event from evolving into a crisis during the adjustment phase, therefore helping the family achieve a state of bonadjustment (McCubbin & McCubbin, 1996).

2.4.1.6 Family appraisal of the stressor [C]

A family's appraisal of a stressor is described as the meaning a family attaches to a stressor event in terms of the seriousness of the stressor and the potential effect it could have on the family system. A stressful event can be appraised as a manageable, constructive challenge that could lead to family growth, or as a destructive, unmanageable catastrophe that could lead to the disintegration of the family unit (McCubbin & McCubbin, 1996). Lavee et al. (1987) distinguished between two forms of appraisal: primary and secondary appraisal. Primary appraisal is the family's assessment of the stressor event and its related hardships. Secondary appraisal evaluates the coping resources the family can utilise in an attempt to deal with the stressful event. Thus, whether or not the stressor event evolves into a crisis ultimately depends on the family's perception of their overall situation, which includes the demands of the stressor event, the family's available resources, and an estimation of the steps or actions necessary to adjust effectively (Lavee et al., 1987).

2.4.1.7 Family problem solving and coping [PSC]

The family problem-solving and coping [PSC] component in the adjustment phase of the Resiliency Model refers to the skills and abilities families utilise in an attempt to manage or eradicate the stress or distress caused by the stressor event. Problem solving involves breaking a stressor and its related hardships down into manageable components; establishing several courses of action that can manage each stressor component; the identification of alternative ways to resolve discrete issues; and the development of constructive, problem-solving communication patterns to restore or maintain harmony and balance within the family unit. Coping involves the active and passive strategies, patterns and behaviours that families implement to (a) strengthen the family as a whole; (b) uphold the emotional stability and well-being of individual family members; (c) acquire and utilise family and community resources that can assist them in dealing with the strains of a stressor event; and (d) manage their active efforts to deal with the hardships caused by the stressor (McCubbin & McCubbin, 1996).

2.4.1.8 Family bonadjustment, maladjustment, and crisis [X]

Most stressors that families face do not create major hardships and seldom result in family distress. If the stressor event is not too great and if the family has the fortitude to withstand the hardship caused by the event, they are able to restore balance and harmony with relative ease and adjust positively to the stressor event without any major adjustments to their traditional patterns of family functioning. The process of positive adjustment is termed bonadjustment and is influenced by the family's ability to appraise the stressor in a positive manner, the availability of established patterns of functioning and effective problem-solving and coping skills, and the family's accessibility to relevant resistance resources (McCubbin & McCubbin, 1996).

However, if the demands of the stressor are too severe to effectively mobilise the family adjustment process, families may need to make significant changes in their patterns of functioning to achieve balance and harmony within the family system. The family experiences a state of maladjustment, which typically results in a condition of family crisis [X]. A crisis is a constant, continuous condition characterised by disharmony, disorganisation, disruptiveness or incapacitation in the family social system. This stage marks the beginning of the adaptation phase of the Resiliency Model (McCubbin & McCubbin, 1996).

2.4.2 Family adaptation

When faced with a family crisis, the family soon realises that their efforts to adjust to the stressor are inadequate. They then enter the adaptation phase (see Figure 2.2). Family adaptation is the course of action families take in an attempt to restore balance between capabilities and demands following a crisis [X], which resulted from their maladjustment to a stressful situation. Adaptation occurs at two levels: (1) between family members and the family unit, and (2) between the family unit and the community (Patterson, 2002a).

they are forced to start the cycle again (McCubbin & McCubbin, 1996). Below is a detailed discussion on the components that play a role in the adaptation process.

2.4.2.1 Family adaptation [XX]

Family Adaptation [XX] can be defined as the outcome produced by the efforts of a family to restore balance and harmony to the family system, following a family crisis situation. The level of family adaptation is determined by the interactions between all the components involved in the adaptation phase of the Resiliency Model (which will each be discussed below), and can range from bonadaptation (at the positive end of the continuum) to maladaptation (at the negative end of the continuum). Bonadaptation is characterised by the successful integration of the demands of a stressor event into the family's established patterns of functioning and involves balance, harmony and fit within the individual-to-family and the family-to-community levels of functioning (McCubbin & McCubbin, 1996).

2.4.2.2 Pile up [AA] of demands

Adaptation is a process that evolves over time and is influenced by the social and cultural environment in which it takes place. Families seldom face a single problem at a time and usually have to deal with a continuous pile up of multiple stressors and strains. If a new stressor surfaces, prior strains are often exacerbated, which could hinder the family's ability to reach a state of balance and harmony (Lavee et al., 1987; McCubbin & McCubbin, 1996).

McCubbin and McCubbin (1996) listed nine categories of stressors and strains that contribute to a pile up of demands within the family system, namely: (1) the initial stressors and its related difficulties; (2) normative transitions – the predictable transitions and changes that result due to the normal growth and development of the family as a whole, as well as its individual members; (3) prior, unresolved strains and stressors that have built up over time; (4) unexpected situational demands and contextual difficulties; (5) the negative consequences of coping strategies that were activated in the past; (6) intrafamily and social ambiguity, which are often exacerbated by inadequate community guidelines regarding effective family coping strategies and support structures; (7) the added strains of newly instituted patterns of

family functioning, which may demand additional changes to family functioning; (8) strains regarding newly instituted patterns of functioning that clash with the family schema or family paradigm; and (9) strains regarding the incompatibility between old, established patterns of functioning and newly formulated patterns of functioning (Lavee et al., 1987; McCubbin & McCubbin, 1996).

2.4.2.3 Family types and newly instituted patterns of functioning [T&TT]

The family typologies employed in an attempt to restore balance and harmony to the family system have a significant influence on the adaptation process of a family dealing with adversity. The Resiliency Model identifies four categories of family typologies or patterns of functioning that plays a role in the adaptation phase: (1) inadequate family patterns of functioning; (2) retained patterns of functioning; (3) restored patterns of functioning; and (4) newly instituted patterns of functioning (McCubbin & McCubbin, 1996).

Families often carry over intact patterns of functioning from the adjustment process into the adaptation phase. Some of these retained family patterns provide harmony and stability to the family system and facilitate the bonadaptation process. However, some family typologies are pathogenic and exacerbate the crisis situation. The presence of inadequate patterns of functioning could be attributed to the deterioration of these typologies while the family was trying to adjust to the stressor event. In some cases, however, the patterns of functioning were inadequate from the very start and were brought over to the adaptation phase despite the negative impact they had on the adjustment process. To optimise adaptation, the patterns of functioning that promote bonadaptation must be preserved, while inadequate patterns of functioning should be eliminated or replaced (McCubbin & McCubbin, 1996).

In the adaptation phase, families are required to make the necessary changes to the family system to promote a state of bonadaptation. The family has to establish new family typologies, and has to assess the effectiveness of these newly instituted patterns of functioning in managing the crisis situation and restoring balance and harmony to the family system. In addition, families may restore or reactivate old patterns of family functioning that the family possessed in the past, but lost over

time. To optimise the adaptation process, families must incorporate the new and restored patterns of functioning into their existing family typologies without undermining the family's established beliefs and values (McCubbin & McCubbin, 1996).

2.4.2.4 Family resources [BB]

Family resources are traits, characteristics or competencies that facilitate the adaptation process. Family resilience can be found in three potential sources, namely the individual family member, the family as a unit, and the community. Family adaptation depends on the family's ability to draw upon established family resources or create new family resources when dealing with the demands of the crisis (McCubbin & McCubbin, 1996).

Family resistance resources are abundant and vary significantly from one family to another, making it difficult to create an exhaustive list of potential resources. Nonetheless, several studies in the field of family research have focused on this topic and discovered numerous family resources that help families to meet the demands of a crisis situation. The family stress and resilience literature has identified eight categories of personal resources that play a significant role in the adaptation process, namely intelligence; knowledge and skills; personality traits; physical, spiritual and emotional health; ethnic identity and cultural background; self-esteem; a sense of mastery; and a sense of coherence. *Family cohesion* – which refers to the bonds of unity between individual family members – and *adaptability* – which involves the family's ability to make the necessary changes to the family system in order to cope with the demands of the crisis – were identified as the most important resources in terms of family system resources. Other pertinent family system resources include family organisation; family problem-solving styles; communication styles; family time and routines; and family hardiness. The community resources that facilitate family adjustment include professional services, organisations and social clubs (McCubbin & McCubbin, 1996).

2.4.2.5 Social support [BBB]

Social support (BBB) can be described as those individuals and institutions that a family and its members can call upon to help them manage the demands of a crisis situation. This can be informal (e.g. extended family, friends) or formal (e.g. medical professionals, schools, churches), and includes the involvement of broader social structures (e.g. the government) as a resilience resource. Furthermore, social support can be divided into five categories, namely emotional support, esteem support, network support, appraisal support and altruistic support. A family's social support is viewed as one of the most important buffers against stress. Furthermore, it predicts family well-being – regardless of the nature of the support (McCubbin & McCubbin, 1996).

2.4.2.6 Family appraisal processes [C to CCCCC]

Family appraisal processes play a vital role in family adaptation. The Resiliency Model distinguishes between five levels of family appraisal: (1) *Schema* [CCCCC]; (2) *Coherence* [CCCC]; (3) *Paradigms* [CCC]; (4) *Situational appraisal* [CC]; and (5) *Stressor appraisal* [C]. The nature of the stressor will dictate the activation of different levels of family appraisal (McCubbin & McCubbin, 1996).

If a stressor event calls for a straightforward, predictable response, the family's traditional problem-solving patterns are usually sufficient in dealing with it. Little to no involvement of the family's schema [CCCCC] or coherence [CCCC] is warranted. Only the first three levels of appraisal, namely paradigms [CCC], situational appraisal [CC] and stressor appraisal [C], will be activated and will play a role in shaping the family's response and behaviour. When faced with a more severe stressor, however, a family's traditional patterns of functioning might be insufficient to deal with the crisis situation. Families might recognise a need for new resources and capabilities. Family paradigms – like family roles, responsibilities, routines, rules and other expectations – may be questioned or challenged, which may warrant the modification of existing patterns of family functioning, or the development of new patterns of family functioning. The shift in the family's patterns of functioning requires the activation of all levels of family appraisal: the family schema [CCCCC]; the sense of coherence [CCCC]; family paradigms [CCC]; situational appraisal [CC]; and stressor appraisal [C].

[C]. The appraisal processes will help the family to assign a new meaning to the stressor event, thus assisting families in altering their perception of the stressor and assessing it as less threatening than in the past. The appraisal processes helps the family to develop a new, unique identity and ultimately strengthens their sense of coherence (McCubbin & McCubbin, 1996).

A detailed discussion on the different levels of appraisal will now follow.

Level 5: Family Schema [CCCCC]

A family's schema [CCCCC] can be defined as "a structure of fundamental convictions, values, beliefs, and expectations" (McCubbin & McCubbin, 1996, p. 39) implemented by the family system over time. It describes the shared expectations, goals, priorities and values of the family and its members that shape their beliefs regarding the outside world and their place in it. Furthermore, it serves as an information framework through which incoming experiences are processed and evaluated and new behaviours are shaped. A family's ethnic and cultural beliefs are also stored in the family schema (Hawley, 2000; McCubbin & McCubbin, 1996).

The family schema plays a significant role in shaping a family's coping strategies, problem-solving responses and patterns of functioning. However, one of its most important functions is to assist the family in developing family meanings. The family schema facilitates the meaning-making process in families through five appraisal functions: (1) affirmation – describing the crisis situation in terms of its positive features and searching for the good that may result from it; (2) classification – explaining the crisis situation in terms of the shared expectations and values of the extended family or tribal structure; (3) spiritualisation – describing the crisis situation in terms of the family's spiritual beliefs; (4) demoralisation – understanding the crisis situation in the context of long-term consequences, whilst still acknowledging the positive features of the present; and (5) naturalisation or contextualisation – explaining the crisis situation in terms of nature and the order of things, or describing it in terms of the community, personal relationships and the interpersonal order of things. Developing a comprehensible meaning for a family crisis makes it more manageable and enables the family to respond to the crisis in an effective manner.

Since family schemas play a central role in the meaning-making process, they also play a vital role in family adaptation (McCubbin & McCubbin, 1996).

Families fostering healthy schemas (a) tend to put emphasis on the collective unit (“we”) rather than focusing on the individual (“I”); (b) usually have a relativistic outlook on life; (c) are more willing to accept less than perfect solutions to problems; and (d) usually show confidence in their ability to overcome difficulties. A healthy family schema is thus a crucial component in the family resilience process (Hawley, 2000).

Level 4: Family Coherence [CCCC]

Family coherence can be described as a global concept that assesses the confidence of families regarding their belief that a stressor event will have a favourable outcome (Hawley, 2000). The family’s sense of coherence is determined by the degree to which their perception of the world is (a) comprehensible, predictable and structured; (b) manageable, with sufficient resources available to deal with hardships; and (c) meaningful and worthy of investment. A family’s beliefs that their efforts will bring about positive outcomes provide them with a motivational basis for converting potential family resources into actual family resources when faced with adverse conditions, thus bringing about the necessary changes in the family system to optimise coping and adaptation (McCubbin & McCubbin, 1996).

Level 3: Family Paradigm [CCC]

Family paradigms [CCC] are defined as the shared rules and expectations adopted or created by families to guide them in the development of patterns of family functioning in relation to specific dimensions of family life. Paradigms are often influenced by the culture and ethnicity of the family and play a significant role in both stressor and situational appraisal (McCubbin & McCubbin, 1996).

Level 2: Situational Appraisal [CC]

Situational appraisal [CC] is a family’s ability to assess their situation. It is dictated by their perception of (a) the nature of the stressor; (b) the additional hardship caused by the stressor event; (c) the availability of coping resources and helpful family

attributes; and (d) the demands on the family unit to modify or alter existing patterns of family functioning. A family's positive appraisal of a stressful situation is positively correlated with adaptation (McCubbin & McCubbin, 1996).

Level 1: Stressor Appraisal [C]

A family's response to a stressful situation depends on the meaning the family bestows on the stressor event. The meaning attributed to the stressor clarifies its inherent issues, proposes possible solutions to the problem, helps manage emotional strain, and empowers families to restore balance and harmony to the family system (Hawley, 2000), thus making it an essential component in the resilience process. Stressor appraisal already takes place in the adjustment phase of the Resiliency Model and is carried over into the adaptation phase (McCubbin & McCubbin, 1996).

2.4.2.7 Family problem solving and coping [PSC]

McCubbin and McCubbin (1996) described the family system as "a resource exchange network in which problem solving and coping occurs" (p. 49). A coping behaviour refers to a specific overt or covert effort families instigate to deal with the demands placed on them due to a stressor event. Coping and problem-solving behaviours are involved in the reduction of stresses, the attainment of family resources, the management of tension in the family system, and the shaping of family appraisal. These coping strategies regularly operate simultaneously, and they are often grouped into coping patterns directed at the management of different elements of family functioning. Coping patterns can be generalised to different stressful events. When coping is considered in terms of a pile up of multiple demands, it seems more practical and relevant to view it as a generalised response to stressful situations, rather than limiting it to a specific reaction (McCubbin & McCubbin, 1996).

In addition to McCubbin and McCubbin's (1996) Resiliency Model, Walsh's (2002, 2003) Family Resilience Framework formed part of the theoretical foundation used in the current study. Walsh (2002, 2003) made a significant contribution to family resilience theory by expanding on the processes that promote family resilience. The key themes and processes apparent in Walsh's (2002, 2003) Family Resilience

Framework can be explained through McCubbin and McCubbin's (1996) Resiliency Model. A better understanding of the resilience process can thus be obtained by integrating these models. Walsh's (2002, 2003) Family Resilience Framework will be discussed in Section 2.5.

2.5 Walsh's Family Resilience Framework

Family resilience is regularly defined in terms of protective and risk factors (Black & Lobo, 2008; Hawley, 2000). A family's protective factors are those resources that buffer the family against the effects of a crisis event and facilitate successful adaptation (Hawley, 2000; Lee et al., 2004; Patterson, 2002a). Risk factors, on the contrary, restrict effective family functioning (Hawley, 2000). Resilience is thus optimised when an adequate amount of protective factors are easily accessible and risk factors are kept to a minimum. Walsh (2002, 2003) expanded on the family resilience literature by identifying three family domains that play a central role in the interactions between risk and protective factors within the resilience process. These domains outline key processes in family resilience that reduce vulnerability and stress during crises, and foster family empowerment, growth and healing. These domains are: (1) family belief systems; (2) organisational patterns; and (3) communication (Walsh, 2002, 2003).

Firstly, family resilience is fostered by shared family beliefs, which mainly comprise of the family's shared values, attitudes, convictions, assumptions and biases. These beliefs help families make meaning of crisis situations, encourage optimism and provide for spiritual support, which in turn aids in healing, growth and problem solving. Family organisational patterns, facilitated by social and economical resources, also improve family resilience and help families to meet the challenges they have to face. The adaptation process necessitates modifications in the family's rules, family roles and family patterns of functioning, thus bringing about changes in the organisational patterns of the family. Flexibility, family cohesion and social and economic resources all have a significant influence on the family's response to these changes. The final domain of family functioning that facilitates family adaptation is communication. Communication processes help bring clarity to ambiguous situations, foster open emotional expression, and promote collaborative problem solving (Walsh, 2002, 2003).

Walsh (2002, 2003) further contributed to family resilience theory by linking it to systems theory, which combines ecological and developmental perspectives in defining family resilience. In this approach, the family is viewed as an open system that develops over a multigenerational life cycle and is highly influenced by its broader socio-cultural context.

According to the developmental perspective, family resilience can be described as an ongoing, adaptive pathway that evolves over time. Most stressors are usually not characterised by a single, static event, but by a complex set of changing conditions that are affected by the past of the family and have a future course that influences future family functioning. The magnitude of a protective or risk factor and its impact on the family is affected by past outcomes and can change over time. The family's expectations regarding family adaptation are influenced by how well they have managed the disruptive nature of past problems and how effectively they reorganised themselves afterwards. Family functioning is constantly assessed as the family system moves forward over time and, as a result, the family's adaptation process evolves continuously (Hawley, 2000; Hawley & DeHaan, 1996; Lee et al., 2004; Patterson, 2002b; Walsh, 1996, 2002, 2003).

An ecological perspective takes into account the different spheres of influence that play a role in family resilience. Walsh (1996, 2002, 2003) views the family as an open system that is influenced by its broader socio-cultural context. A family's unique perspectives, challenges and resources, combined with the larger historical, cultural and social system in which it functions, have a significant effect on family resilience. It is thus crucial to consider the unique context of a situation when assessing an adaptive pathway that will facilitate the family's resilience process (Hawley, 2000; Patterson, 2002a; Walsh, 1996).

The pathway to resilience is unique for each family, making it difficult to discover a one-size-fits-all blueprint for family resilience (Hawley, 2000). Walsh (1996, 2002, 2003) combined both ecological and developmental perspectives to explain the idiosyncratic nature of family resilience. It was explained that family resilience evolves over time and could be hindered by the pile up of demands. Furthermore, how each family responds to a stressful situation will differ, depending on the socio-

cultural context they find themselves in. Nonetheless, Walsh (2002, 2003) identified three family domains that were common to most high-functioning families. Family resilience can be optimised by strengthening these family processes (Walsh, 2002, 2003).

2.6 Motivation for Selecting the Theoretical Framework Used in the Present Study

Family resilience offers an explanation for how some families become and stay healthy despite adverse conditions, while others fall apart (Black & Lobo, 2008). McCubbin and McCubbin's (1996) Resiliency Model and Walsh's (2002, 2003) Family Resilience Framework, which form the theoretical foundation of the current study, provide a way of measuring the outcome of the resilience process. Several South African studies on family resilience have used these models as a baseline for their research (e.g. Bester, 2009; Greeff et al., 2006; Greeff & Thiel, 2012; Greeff & Wentworth, 2009; Jonker & Greeff, 2009).

The Resiliency Models used in this study are both grounded in positive psychology. They both focus on family strengths rather than on pathology. While these positive, future-orientated approaches do not disregard past problems, they do promote a forward-looking view that focuses on how families can succeed, rather than fixing their attention on past failures. They shift focus away from how problems were caused, towards how problems can be resolved. Furthermore, they redirect assessment and intervention resources towards identifying and amplifying existing and potential strengths, rather than on repairing family weaknesses (Hawley, 2000; Walsh, 2002, 2003).

McCubbin and McCubbin's (1996) Resiliency Model and Walsh's (2002, 2003) Family Resilience Framework also acknowledge the effect of time on family resilience as families evolve across the life cycle. The functioning of a family residing with a family member diagnosed with a chronic illness is influenced by both the development of the illness, and the normative life cycle changes they have to go through. The unfolding of a chronic illness, like dementia, should thus be viewed in a developmental context. By considering resilience as a developmental pathway, the Resiliency Models used in this study are capable of looking both backward and

forward in time when assessing families. They provide families with a forward-looking psychosocial map that normalises and contextualises their experiences. The family Resiliency Models used in the current study humanise the illness and its challenges, which helps maintain family morale. This is particularly beneficial when dealing with families caring for a chronically ill patient, who often feel abnormal or lacking compared to their “normal”, “healthy” peers who are not dealing with an illness situation (Walsh, 2002). In addition, these family Resiliency Models foster family empowerment. Rather than viewing distressed families as “victims of their past” (Hawley, 2000, p. 107), they acknowledge the reparative potential of these families and help families to learn from their past struggles. These family resilience frameworks strengthen families by integrating their past experiences with their present lives, thus helping them to emerge stronger and more resourceful. By building the family’s resilience, family vulnerability is reduced and families are better able to deal effectively with future challenges. In this way, strengthening family resilience can be deemed a preventive measure (Hawley, 2000; Walsh, 2002, 2003).

Well-functioning families can be found in diverse family arrangements. Thus, it is deemed crucial to consider the social and cultural context of the family when measuring family functioning. The family resilience framework ensures ethnic and cultural validity by assessing family functioning in context, relative to the structure, values, resources and life challenges faced by the family (Walsh, 2002, 2003). McCubbin and McCubbin’s (1996) Resiliency Model and Walsh’s (2002, 2003) Family Resilience Framework thus relate to a wide range of populations and problem situations, which is essential in the culturally diverse South African context.

In conclusion, the advantages posed by McCubbin and McCubbin’s (1996) Resiliency Model and Walsh’s (2002, 2003) Family Resilience Framework act as motivation for the selection of these models as the theoretical framework of the current study. They are both strength based and focus on overcoming adversity. Furthermore, they are both grounded in the belief that families hold the potential to recover and grow from adverse conditions. Both McCubbin and McCubbin’s (1996) Resiliency Model and Walsh’s (2002, 2003) Family Resilience Framework are also grounded in ecological and developmental perspectives, thus assuming that no single model fits all families or situations and that family functioning should be

measured with regard to the family's socio-cultural context and life cycle stage (Walsh, 2002, 2003). These advantages prove the relevance of these frameworks within both the South African context and in the lives of families caring for family members suffering from a chronic illness, like dementia.

2.7 Conclusion

Chapter 2 elaborated on the central concept of the current study – family resilience. The definition and evolution of family resilience was explored, followed by a summary of the development of the family stress and Resiliency Models. Furthermore, the resilience process was explained through McCubbin and McCubbin's (1996) Resiliency Model of Family Stress, Adjustment and Adaptation and Walsh's (2002, 2003) Family Resilience Framework, which form the theoretical foundation of this study. These models simplify the resilience process by isolating individual, family and community features that interact with each other to shape family behaviour. These features can be classified in terms of stressors, protective factors and risk factors, and influence families' ability to adjust and adapt when faced with crises. By isolating these features, important family resilience factors can be identified and, if understood, become targets for future intervention strategies. The next chapter will focus on the relevant literature that examines resilience factors in families caring for family members diagnosed with dementia.

CHAPTER 3

LITERATURE REVIEW

3.1 Introduction

A literature search on family resilience factors in families caring for a dementia patient was conducted via the electronic databases EBSCOhost (Academic Search Premier and PsycARTICLES), Web of Science (1970 to present), Google Scholar, and the electronic thesis database of Stellenbosch University. The keywords used in the search included “dementia”; “family resilience”; “family adaptation”; “family resilience” and “dementia”; “family adaptation” and “dementia”; “coping” and “dementia”; and “family resilience” and “chronic illness”. The references of the literature found were also reviewed to identify additional citations. The literature search delivered no studies on family resilience factors in families caring for a dementia patient. However, several studies were found on factors that buffer caretaker burden in families caring for a dementia patient (Davis, 1997; Gottlieb & Rooney, 2004; Haley et al., 1987; Haley et al., 1996; Quinn et al., 2008).

It should be noted that there are several differences between the study of resilience on the individual level and the study of resilience on the family level. Individual resilience studies focus on resilience within single persons, while family resilience studies use the family as the unit of analysis; resilience may take on a different nature at varying levels of analysis. Nevertheless, there are some similarities between the two sets of literature. In both cases, resilience develops in response to a stressful situation, and both levels emphasise the ability to “bounce back” to a previous level of functioning when faced with hardship. Furthermore, both levels stress the significance of context when predicting resilient outcomes. The current study, which focuses on the more recently established family resilience paradigm, could thus benefit from examining the wider range of studies that focus on individual resilience in dementia caregivers (Hawley & DeHaan, 1996). Furthermore, a significant positive relationship exists between the individual resilience characteristics of family members and family resilience (Jonker & Greeff, 2009). Consequently, the studies found on factors that buffer caretaker burden in families caring for a dementia patient were included in the literature review.

Several studies were also found on the resilience of families caring for family members suffering from other chronic illnesses, i.e. cardiovascular diseases (Greeff & Wentworth, 2009); brain injury (Carnes & Quinn, 2005); mental illnesses (Bester, 2009; Greeff et al., 2006; Jonker & Greeff, 2009); cancer (Greeff & Thiel, 2012); and fibromyalgia syndrome (Preece & Sandberg, 2005). Although some features of specific illnesses may differ, there are several commonalities between families caring for dementia patients and families caring for patients with other chronic illnesses. Similar variables were found to influence family resilience across multiple different studies (Walsh, 2002). The studies addressing resilience in families caring for patients with other chronic illnesses were thus included in the literature review, since the results obtained in these studies might also apply to the current research population.

The family members of dementia patients also have to deal with feelings of loss and grief due to the deterioration of their relationship with the patient (Davis, 1997; Sadock & Sadock, 2007; Schulz & Martire, 2004; Zarit et al., 2010). The family resilience factors utilised by families grieving for a loved one who has passed away might thus also apply to families in which a family member has been diagnosed with dementia. Consequently, family resilience studies on families dealing with the death of a family member (Greeff & De Villiers, 2008; Greeff & Joubert, 2007) were also included in the literature review.

As mentioned in the previous chapter, Walsh (2002, 2003) identified three family domains that promote family resilience during crisis situations: (1) family belief systems; (2) organisational patterns; and (3) communication (Walsh, 2002, 2003). The following sections will discuss the results of the literature search by applying them to these family domains. However, the impact of the initial stressor will be discussed first.

3.2 The Impact of an Illness Stressor on the Family

In McCubbin and McCubbin's (1996) Resiliency Model, the resilience process is initiated by a stressful event that disrupts family functioning and leaves the family in a state of imbalance and disharmony. The family's appraisal of this stressor event is influenced by the extent to which the stressor threatens the stability of the family

system and drains the family's resources (McCubbin & McCubbin, 1996). When caring for a chronically ill patient, the objective severity of the patient's illness might have a significant effect on family adaptation.

Bester's (2009) study, which examined the resilience qualities present in families in which a parent has been living with depression, also found a significant relationship between the severity of the patient's cognitive impairment and family adaptation. In this study, an explorative-descriptive research design was used in which the participants were asked to complete a biographical questionnaire, a qualitative open-ended question, and a set of quantitative self-report questionnaires. The study population consisted of current or ex-South African National Defence Force members who used the military's medical aid. The families of 36 patients were recruited to participate in the study using a non-probability purposive sampling procedure. The families were represented by both spouses ($n = 34$) and children ($n = 27$). The Family Attachment and Changeability Index 8 (FACI8) was used to measure the dependent variable (family adaptation), while other family variables were measured with the Family Crisis Orientated Personal Evaluation Scale (F-COPES); the Family Hardiness Index (FHI); the Family Problem Solving and Communication Scale (FPSC); the Family Time and Routine Index (FTRI); the Relative and Friend Support Index (RFS); and the Social Support Index (SSI). Furthermore, Beck's Depression Inventory was completed by the patients to measure the severity of their depression. Bester (2009) found a statistically significant, negative correlation between the depression levels of the patient and family adaptation. These findings echoed Carnes and Quinn's (2005) study of factors related to family adaptation to brain injury. Carnes and Quinn (2005) used a convenience sampling method to recruit participants in Georgia, USA. Data was collected from 123 family members of 65 brain-injured patients and analysed using hierarchical linear modelling. Carnes and Quinn (2005) found that the patient's level of emotional and behavioural change had a significant impact on individual factors in family members, like psychological distress. However, these results were not found on a family level. Emotional and behavioural change were not correlated with family functioning. These seemingly contradictory results were attributed to the ability of family members to band together in an attempt to deal with the patient's emotional and behavioural changes, which buffered some of the strain on family functioning.

Pattanayak et al. (2010) assessed various areas and predictors of caregiver burden in Indian dementia caregivers. A sample of 32 patient-caregiver dyads was recruited from the dementia clinic of a tertiary care hospital in New Delhi, India. Both the patient and the key caregiver were assessed. Pattanayak et al. (2010) found that the duration of the illness and the severity of the patient's cognitive impairment were significant predictors of higher caregiver burden in the family of caregivers of dementia patients. Haley et al. (1987), who studied the predictors of individual differences in caregiver adaptation, found that the relationship between caregiver outcomes and the severity of objective caregiving stressors was relatively weak. In their study, a stress and coping model was used to study predictors of individual differences in caregiver adaptation. A sample of 54 family caregivers caring for elderly patients with dementia was asked to complete a series of structured interviews and questionnaires measuring stressors, appraisal, coping responses, social support, depression, life satisfaction and health. In a stepwise regression analysis, the severity of objective caregiving stressors accounted for very little of the variance in life satisfaction, caregiver depression and health. However, 26.5% of the participants mentioned positive patient behaviour as a factor that facilitated coping.

3.3 Family Belief Systems

3.3.1 Making meaning of adversity

The severity of a crisis is shaped by a family's subjective appraisal of the situation. A family's response to a stressful situation depends on the meaning the family bestows on the stressor event, which is influenced by family schema, family paradigms, and the family's sense of coherence (McCubbin & McCubbin, 1996). When faced with unexpected crises, families often attempt to understand why the event happened to them and how they should react to the situation. The total situation is appraised relative to the demands of the crisis situation, the perceived presence of other stressors, the family's perceived capabilities and coping resources, and the coping options they believe are available to them. This meaning-making process influences the family's ability to come to terms with and accept the crisis event and their competence in selecting an adequate coping response, thus playing a major role in family adaptation (Hawley, 2000; Lavee 1987; McCubbin & McCubbin, 1996; Patterson, 2002a, 2002b; Walsh, 2003).

When faced with hardship, families do best when helped to gain a sense of coherence. By reframing a problem as a challenge that is comprehensible, manageable and meaningful to tackle, families are able to maintain a sense of control over their internal and external environments. Normalising and contextualising problems help family members to see their reaction to crisis situations as understandable, which fosters confidence that their circumstances will ultimately work out in a favourable way (Hawley, 2000; Lavee 1987; McCubbin & McCubbin, 1996; Walsh, 2003).

Several studies have found a significant correlation between family resilience and ascribing meaning to a crisis situation. Bester (2009), who examined the resilience qualities present in families in which a parent had been living with depression, found a statistically significant relationship between family adaptation and passive appraisal, which indicated that resilient families accepted their situation and minimised their reactivity towards it. The regression analysis of the child data strengthened these findings when it revealed that the passive appraisal of a stressor contributed statistically significantly to the prediction of family adaptation. Family adaptation was also positively correlated with the ability of families to redefine a crisis situation and ascribe a new meaning to it for both the spouse and child populations (Bester, 2009).

Greeff et al. (2006), who examined resilience characteristics that helped families with a member with a mental disorder to adapt to their circumstances, found similar results. A cross-sectional, correlational and exploratory research design was used in this study. Data was collected from 30 participating families via a mixed-methods approach. A parent and a child from each family were asked to complete a biographical questionnaire and to answer an open-ended question regarding coping strategies, resources and strengths that helped them through difficult times. The participants were also asked to complete the following questionnaires: the Family Crisis Oriented Personal Evaluation Scale (F-COPES); the Social Support Index (SSI); the Family Hardiness Index (FHI); the Relative and Friend Support Index (RFS); and the Family Sense of Coherence Scale (FSC). A relatively strong positive correlation was found between the redefinition of a crisis situation and adaptation in the children subgroup. However, this correlation was not evident in the parent

subgroup and, in the responses to the open question, only some parents indicated that they used this strategy. However, there was a significant positive correlation between the passive evaluation of a crisis situation and family adaptation in the parent subgroup (Greeff et al., 2006).

Carnes and Quinn (2005), who investigated factors related to family adaptation when a family member has a brain injury, also made use of the Family Crisis Orientated Personal Evaluation Scale (F-COPES) to measure family coping resources. The reframing of the situation had a significant relationship with both decreased psychological distress and increased family functioning. However, no significant correlations were found between family functioning and passive appraisal. Carnes and Quinn (2005) made use of the Family Adjustment and Adaptation Response (FAAR) Model as a theoretical framework and noted that the appraisal factor [CC] was the least investigated factor in the model. They reasoned that this might be due to the difficulty of operationalising and measuring the meaning-making process, thus implying a need for better instruments to assess this factor.

Even though Greeff and Wentworth (2009) did not mention the importance of the meaning-making process, they did identify the ability to reformulate a problem situation as a key resilience factor. They conducted a study that focused on family qualities associated with adaptation following a heart-related crisis in the family. A cross-sectional survey research design was utilised and the participants were asked to complete an open-ended question and several self-report questionnaires. The questionnaires used to collect the necessary data were the Family Hardiness Index (FHI); the Family Time and Routine Index (FTRI); the Social Support Index (SSI); the Family-Crisis Oriented Personal Evaluation Scales (F-COPES); the Family Problem Solving Communication questionnaire (FPSC); the Relative and Friend Support Index (RFS); and the Family Attachment and Changeability Index 8 (FACI8). Twenty-two families from the Western Cape, South Africa participated in the study. The questionnaires were completed by the parent who had experienced the heart-related crisis. These researchers found a significant positive correlation between the reframing of a crisis situation and family adaptation.

Greeff and Thiel (2012) also found a significant positive relationship between the reframing of a crisis situation and family adaptation. Their study examined the resilience of families with a husband that was diagnosed with prostate cancer. Data was gathered in the Western Cape, South Africa through a cross-sectional survey research design in which both the husband and wife of the participating family were asked to answer an open-ended question and complete six self-report questionnaires – viz. the Family Attachment and Changeability Index 8 (FACI8); the Family Hardiness Index (FHI); the Social Support Index (SSI); the Relative and Friend Support Index (RFS); the Family-Crisis Oriented Personal Evaluation Scales (F-COPES); and the Family Problem Solving Communication questionnaire (FPSC). Twenty-one husbands and their wives successfully completed the measuring instruments. The results from the wives subgroup showed a significant positive relationship between family adaptation and the reframing of stressful events. Even though the correlation between family adaptation and reframing in the husband subgroup was not statistically significant, there seemed to be a positive tendency between the two variables, which might imply a possible relationship. However, no significant relationship was found between family adaptation and passive appraisal.

Jonker and Greeff (2009) conducted a study on resilience factors in families living in an underprivileged, semi-rural area who were caring for a family member with a mental illness. A mixed-methods, cross-sectional survey research design was used. Data was obtained from 34 families from the Western Cape Province, South Africa using semi-structured interviews and a set of seven self-report, quantitative questionnaires. The Family Attachment and Changeability Index 8 (FACI8) was used to measure the level of family adaptation (the dependent variable). The independent variables were measured using the Social Support Index (SSI); the Relative and Friend Support Index (RFS); the Family Problem Solving and Communication Scale (FPSC); the Family Hardiness Index (FHI); the Family Crisis Oriented Personal Evaluation Scales (F-COPES); and the Family Time and Routine Index (FTRI). In this study, 32.4% of the participants reported that understanding the patient and the illness helped the family adjust to their situation. In contrast to other family resilience studies, however, Jonker and Greeff (2009) found a significant negative correlation between passive appraisal as a coping style and family adaptation. This premise was strengthened by the results of the multiple regression analysis, in which passive

appraisal also showed a negative relationship with family adaptation. The results thus imply that it is more beneficial to deal with crises proactively than to passively accept the situation.

The importance of the meaning-making process is also emphasised in studies on caregiver burden in families caring for a dementia patient. Haley et al. (1987) found that depression in caregivers was better predicted by the subjective appraisals of problems faced when caring for a dementia patient than by the objective severity of these problems. The study found that the subjective feelings of caregivers regarding behavioural problems and disability in patients, and their own self-confidence in managing these problems, played a significant role in predicting depression. In addition, logical analysis, affective regulation and information seeking, which facilitate the meaning-making process, were related to higher self-reported health.

Family values and beliefs that facilitate the meaning-making process vary with different cultural norms (Walsh, 2003). In a study by Haley et al. (1996), the role of appraisal, coping and social support as mediators of well-being in black and white family caregivers of patients with Alzheimer's disease was investigated. A sample of 123 white and 74 black caregivers was recruited as part of a larger project through the Memory Disorders Clinic at the University of Alabama at Birmingham (DAB). The participants had to complete a structured interview and questionnaire. The study showed a relationship between lower appraisals of the subjective stressfulness of caregiving stressors and lower levels of depression. Furthermore, the study explored the impact of race on appraisal and coping responses. The study found that black caregivers scored the subjective stressfulness of caregiving stressors lower than did white caregivers. The study hypothesised that the racial differences in appraisal and coping might be due to the differences in life experiences between black and white caregivers, or due to cultural differences. The study found that white caregivers were more likely to report that taking on the role of caregiver was unexpected and disrupted their life plan. Conversely, black caregivers reported caregiving as an expected experience, thus being less disruptive. Similar results were found by Haley et al. (2004), who conducted a study in which African-American and Caucasian dementia caregivers were compared in terms of mental and physical well-being, appraisal and potential coping resources. The study sample consisted of 720 primary

family caregivers (425 Caucasian and 295 African-American) from Birmingham, Boston, Memphis, and Philadelphia, USA. Data was collected via in-home interviews. African-American caregivers' subjective appraisals of stressfulness were lower than the appraisals by Caucasian caregivers. African-American caregivers also reported greater benefits or self-gain from caregiving. The difference in appraisal between Caucasian and African-American caregivers was ascribed to factors like prior experience with adversity, previous experience in caregiving roles, expectations that caregiving will occur, and cultural support for caregiving.

In the context of dementia caregiving, the meaning-making process is facilitated by the availability of adequate information regarding the causes of dementia, treatment options available to dementia patients, and resources that could help caregivers and their families to cope with their situation. In the Handbook of Clinical Neurology (Chapter 9: Dementias), Zarit (2008) discusses factors that facilitate the management of burden in dementia caregivers. Zarit (2008) mentions that well-informed caregivers who understand that the altered behaviour of a dementia patient is due to the underlying brain disease, and not an intentional act, are often more adaptive and able to respond in a way that relieves some of the stress they have been experiencing, thus reducing depression. Sources of information mentioned in this chapter include self-help books, structured educational programmes, community-based support groups, and informational sessions provided by voluntary organisations like the Alzheimer's Association.

Yamashita and Amagai (2008) also recognise the importance of knowledge when caring for a dementia patient. They explored the experiences of family caregivers in Japan caring for a relative with dementia using a phenomenological approach. Twelve family caregivers, who lived or had recently lived in the same households with their relative diagnosed with dementia, were interviewed. Those participants who actively sought information regarding the illness and caring for their elder tended to report their caregiving experience more positively. These participants attended support group meetings or lectures run by the local government or non-profit organisations.

Quinn et al. (2008) conducted a phenomenological study exploring the subjective psychological experiences of spouses and co-resident partners of individuals with early-stage dementia. Thirty-four dementia caregivers, from both urban and rural areas in the south of England, were interviewed by either a clinical psychologist or a clinical psychologist in training using a semi-structured interview schedule. The participants reported difficulties in understanding and accepting the diagnosis of their loved ones. This lack of understanding influenced how they understood the impact of the illness on the dementia patient, thus leading to misunderstandings regarding problematic behaviour. Dementia caregivers need to understand and make sense of the diagnosis and the changes brought about by the illness, before they can adjust to their situation. Due to a lack of knowledge regarding dementia, caregivers often attribute problematic behaviour to the patient rather than to the illness, which could have a negative impact on the adjustment process. Well-informed caregivers were better able to cope with these problematic behaviours on a day-to-day basis.

The importance of information seeking in the family resilience paradigm was discussed in Greeff and Thiel's (2012) study on resilience in families where a husband was diagnosed with prostate cancer. The results of the qualitative question showed that both wives and husbands deemed information seeking as an important means to deal with crisis events. Greeff and Thiel (2012) explain that knowledge regarding the cause, treatment and prognosis of the illness helped the families to accept the reality of their situation and eased their anxiety. Knowledge of the illness also made family members feel more involved in the decision-making process, thus promoting a sense of control in an otherwise uncontrollable situation.

3.3.2 Positive outlook

An optimistic view of life, which fosters hope for the future, empowers families to rise above adverse circumstances. Unlike families in denial, hopeful families are still aware of reality, such as a poor prognosis, but choose to make the most of the options available to them, in spite of the problems they are facing. Optimism is upheld in families who accept factors beyond their control and who focus their efforts on future possibilities and opportunities (Black & Lobo, 2008; Walsh, 2003).

Optimism can be learned through the successful mastery of problem situations. Affirming family potential and strengths and learning how to reframe crises in such a way that they seem manageable, reinforce confidence, pride and a “can do” attitude, which in turn facilitate the family adaptation process. Feelings of blame, shame and guilt can be reduced by normalising and contextualising the distress of family members regarding the crisis situation. Family members can also motivate each other to take initiative, seize opportunities, and search for solutions instead of just giving up under difficult circumstances (Walsh, 2003). Furthermore, family members can encourage optimism in each other through displays of affection, humour, offering positive solutions, and accepting suggestions (Black & Lobo, 2008).

Greeff and De Villiers (2008) conducted a study that focussed on the effect of hope and optimism on family adaptation in single-parent families after the death of a parent. The participating families were represented by a child. Data was collected using a cross-sectional survey research design in which a semi-structured interview was conducted with 22 students from the Western Cape, South Africa. The participants were also asked to complete the Family Attachment Changeability Index 8 and the State Hope Scale. The study confirmed that higher levels of optimism and hope correlated with better family adaptation. The answers to the open-ended question revealed several manifestations of positivism and optimism in a family's dealing with the death of a parent. Greeff and De Villiers (2008) identified the positive attitudes of individual family members as the most important manifestation of optimism and positivism. The thoughts and behaviour of a positive family member whose personal characteristics include optimism could shift the focus of an entire family to a future in which their loss no longer has a stressful effect on family functioning, and in which things once again were better for everyone. Other manifestations of positivism and optimism included closeness within the family; mutual support; focusing on the positive; an appreciation for what they have; improving the self and striving towards personal success; an inclination to move on; religious beliefs; and humour (Greeff & De Villiers, 2008).

Greeff and Wentworth (2009), who conducted a study on family adaptation following a heart-related crisis in the family, also described the importance of optimism in the family resilience process. They found that a positive outlook, and an understanding

and acceptance of new circumstances, had a positive relationship with family adaptation.

Gottlieb and Rooney (2004) found that optimism had a significant impact on the perceived coping effectiveness in the family caregivers of dementia patients. The Gottlieb and Rooney (2004) study focused on the family caregivers of individuals with dementia and their methods of coping; their effectiveness in coping with challenging symptoms displayed by their relative; their general and specific outcome expectancies; their positive and negative affect; and their mental health. Data was collected from 141 family caregivers who lived in a large Eastern Canadian metropolis. The participants were mostly spouses (36.9%) and children (63.1%) who provide home-based care to relatives with dementia, mainly of the Alzheimer's type. A team of five interviewers contacted participants and conducted a home interview in which standardised scales were administered. They found that optimism had a consistent and relatively strong influence on coping behaviours, coping effectiveness and outcome expectancies (Gottlieb & Rooney, 2004).

In a dementia caregiving context where there is little hope for cure, caregivers have to accept the prognosis of their situation if they are to adapt successfully. Quinn et al. (2008) conducted a study on the subjective experiences of spouses and co-resident partners of individuals with early-stage dementia. They found that dementia caregivers often make use of an emotion-focused coping strategy, in which they tried to cope on a day-to-day basis. These families avoided thoughts about the future. The caregivers were aware of the prognosis of the illness, but realised that they could not change anything about the diagnosis and had to accept it. The caregivers emphasised positivism and the need to enjoy their time left with the patient.

In the study by Haley et al. (1996) on racial differences in appraisal, coping and social support in family caregivers of patients with Alzheimer's disease, a significant difference was reported between the coping strategies of white and black caregivers. White caregivers more often made use of both approach and avoidance coping strategies. Approach coping was linked to higher levels of life satisfaction and lower levels of depression; on the contrary, avoidance coping correlated with lower levels of life satisfaction and higher levels of depression.

Family hardiness facilitates an optimistic family outlook and is an important component of family resilience. Family hardiness is characterised by mutual dependence and the ability to work together as a family unit. Families with high hardiness scores do not view change as a threat, but rather as a normal part of life that could bring about opportunities for growth. They participate actively in life events and believe that they have a significant influence on eventual outcomes (Greeff et al., 2006).

Preece and Sandberg (2005) identified higher levels of family hardiness as an inherent component of family resilience. The purpose of their study was to investigate the relationship between family resilience and the effective management of the symptoms of fibromyalgia syndrome (FMS). The sample used in their study consisted of 150 patients diagnosed with FMS. The participants were asked to complete an online survey, which consisted of a questionnaire packet that included the Fibromyalgia Impact Questionnaire (FIQ); the Family Index of Regenerativity and Adaptation – General (FIRA-G); the Chronic Pain Coping Strategies Questionnaire (CPCS); the Health Care Utilization Survey (HCUS); and a demographic questionnaire. They found that family hardiness had a significant positive correlation with the patient's well-being. Family hardiness correlated negatively with psychological distress, self-reported health problems and functional disability, and positively with the utilisation of positive pain-coping skills.

Several other studies have also identified family hardiness as an effective resilience quality. Both spouses and children in Bester's (2009) study of the resilience of families in which a parent was living with depression indicated a statistically significant correlation between family hardiness and family adaptation. These results are further supported by Greeff and Wentworth (2009), who identified family hardiness as a key resilience quality. Family hardiness was also identified as an important resilience factor by both the parents and the children in the study by Greeff et al. (2006) on resilience in families with a member diagnosed with a mental disorder. Greeff and Thiel (2012), who studied resilience in families with a husband diagnosed with prostate cancer, also observed a positive relationship between family resilience and family hardiness. An overall significant positive correlation was found between these variables for both husbands and wives. However, the analysis of the

subscales of the Family Hardiness Index only found statistically significant results for the wives subgroup. A statistically significant positive correlation was found between family adaptation and the commitment and control components of family hardiness. In the husbands subgroup, no statistically significant correlation was found between family adaptation and any of the components of family hardiness. Greeff and Thiel (2012) explain that this inconsistency might be due to the relatively low internal reliability of the subscales in their study.

Family hardiness is characterised by self-efficacy – a feature that describes how individuals evaluate their family's ability to successfully master a specific task. Individuals with a high sense of caregiving efficacy focus on their own strengths and what they are capable of accomplishing, rather than on their failures. This positive attitude regarding their own skills protects them – and therefore their family – from the negative consequences of caring for a chronically ill family member.

Gilliam and Steffen (2006) studied the role of self-efficacy in the relationship between the objective primary stressors of dementia caregiving and caregiver depressive symptoms. Seventy-four women caring for a family member with dementia were recruited from nine central US states (Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska and Wisconsin). Data was only collected from primary caregivers with depressive symptoms. In this study, 52.2% of the participants were caring for a husband, 44% were caring for a parent, and less than 5% were caring for other family members (grandparent, aunt, or mother-in-law). The participants completed a telephonic interview and self-report questionnaires that included measures on caregiving self-efficacy and depressive symptoms. A significant negative relationship between self-efficacy and depressive symptoms was found, even after controlling for the level of cognitive impairment or the behavioural problems that the caregivers face.

Similar results regarding self-efficacy were found by Au et al. (2009). They conducted a study in Hong Kong, investigating the mediating role of self-efficacy in the relationship between social support and depressive symptoms in the caregivers of dementia patients. Self-efficacy was measured in terms of controlling upsetting thoughts; obtaining respite; and managing disturbing behaviour. One hundred and

thirty-four caregivers, who mostly were spouses (29.1%), adult children (57.5%) and daughters- or sons-in-law (7.5%), participated in this study, in which they were asked to complete a series of questionnaires measuring social support, self-efficacy and depressive symptoms. In addition, structured interviews were conducted before or after the appointments. It was found that the caregivers' levels of self-efficacy had a negative correlation with depressive symptoms, which suggests a significant positive relationship between higher self-efficacy, well-being and resilience.

3.3.3 Transcendence and spirituality

Spiritual beliefs and practices play a central role in family adaptation. Spirituality is connected to a family's shared internal value system, which plays a central role in the family's meaning-making process. These beliefs and practices provide families with meaning and purpose beyond themselves and their immediate problems, and tend to create a feeling of connectedness between families and their members, the community and the universe. Spiritual resources, like faith, religious/congregational affiliation, cultural/religious traditions, and spiritual practices, such as prayer and meditation, provide families with guidance, comfort and strength and help them to understand and overcome crisis situations. In addition, religious or congregational affiliation offers a linkage with a larger community, which could provide support to family members facing adverse conditions (Black & Lobo, 2008; Walsh, 2003).

Greeff and Joubert (2007) conducted a qualitative study on the effects of spirituality on the adaptation process after the loss of a parent. The families recruited for the study all resided in suburban areas in the Western Cape, South Africa and had at least one child living at home. In this study, semi-structured interviews were conducted with 25 widowed parents (19 women and 6 men). Most of the participants believed that religion was "the rock" that facilitated family adaptation after the death of a parent. The majority (80%) mentioned that, in the process of loss and suffering, their faith had grown stronger and that they felt closer to God or were more aware of God's presence. Half of the participants (50%) believed that God knows best and that He is ultimately in control. They believed that He would not let something like death in the family happen without a reason. Another prominent theme was the idea that the loved one would be seen again when the family reunited in Heaven; the separation was thus only temporary. Furthermore, the shared beliefs of the parents

and children bound them together, comforted them, and gave them a sense of hope, security and support. However, the death of a loved one could have a negative influence on spirituality or religion. One family became atheistic after the death of a parent because they could not fathom how a God of love could do this to them.

Other family resilience studies have shown mixed results regarding the effect of spirituality on family adaptation. Carnes and Quinn (2005) found a significant positive relationship between family functioning and spiritual support as measured by the F-COPES. In Bester's (2009) study on resilience qualities present in families with a parent living with depression, the children's data also revealed a significant positive relationship between seeking spiritual support and family adaptation. Greeff et al. (2006), however, found no significant relationship between these variables. Greeff et al. (2006) argued that the need to search for spiritual support might be less due to the variety of options available to families to help them cope when living with a mentally ill family member. Greeff and Thiel (2012) reported mixed results regarding spirituality as a resilience factor. In the qualitative data, both husbands and wives reported that spirituality had a positive impact on family adaptation. These results were not supported by the quantitative data, which showed no correlation between spiritual and religious beliefs and family adaptation. Similar results were found in an earlier study by Jonker and Greeff (2009), which focused on family resilience in families caring for a mentally ill family member. Their quantitative analysis also showed no significant correlation between family adaptation and religion and spirituality as a family coping strategy. However, in contrast to the quantitative findings, 67.6% of the participants mentioned the role of religion and spirituality in family adaptation in the qualitative interviews. Jonker and Greeff (2009) explain that this inconsistency found in the answers of participants might be due to the ambiguity of the spiritual support items in the Spiritual support subscale of F-COPES, which was used to measure spirituality as a family coping strategy in both of these studies.

No studies that focus on dementia care specifically identified a significant relationship between spirituality and coping. Yamashita and Amagai (2008), who explored the experiences of family caregivers in Japan caring for a relative with dementia, found that the participants failed to mention faith in God's help as a coping strategy. They attribute this to the ambiguous nature of religiosity as a concept,

which might be included in other concepts, like finding meaning in the caregiving role. The lack of religiosity as a coping mechanism might also be due to caregivers taking on a worldview that is existential in nature. However, in the study by Haley et al. (1996), who examined racial differences in appraisal, coping and social support as mediators of well-being in family caregivers of Alzheimer's patients, it was found that the majority of both white (87.5%) and black (90.4%) family caregivers made use of religion as a coping mechanism. Church-related behaviours and coping did not differ by race, and most caregivers from both races were members of a church. No significant racial differences were found regarding mean scores on use of prayer, church attendance and church group meetings either.

3.4 Family Organisational Patterns

3.4.1 Flexibility

Most crisis situations require families to construct a new sense of normality that better accommodates their situation. Flexibility is thus a vital process in resilience, which helps families to view inevitable changes more optimistically and allows them to adjust to new circumstances. However, a lack of rules and routines fosters a chaotic family environment characterised by inconsistency, unpredictability and role confusion, which could ultimately lead to conflict and estrangement. Families need some stability and continuity to help them hold on to who they are and to maintain their integrity as a system. Daily routines and rituals provide families with feelings of cohesion, comfort and predictability, which buffer and counterbalance the disruptive effects of change. Families thus tend to function best when a sense of balance is achieved between flexibility and stability or structure (Black & Lobo, 2008; Patterson, 2002b; Walsh, 2003).

The results obtained in Greeff and Wentworth's (2009) study on key family qualities associated with family adaptation following a heart-related crisis showed that flexibility plays a major role in family adaptation. When a family member experiences a health crisis – in this case, heart-related trauma – the patient is often incapable of carrying out former responsibilities. Other family members need to take over the different roles that can no longer be fulfilled by the patient and have to adjust to new chores and routines, while attempting to maintain the same level of functioning. The

family's ability to adapt to these role changes plays an important part in the recovery process.

In addition, Greeff and Wentworth (2009) found that family time and routines seem to be an important quality in mediating family adaptation. Stability in family time and routines could have a positive effect on how the family reacts to the challenges they have to face. The study identified family routines that promote child and adolescent responsibilities in the home as an important factor in family resilience. This importance was confirmed by the significant positive correlation found between family chores, as measured by the Family Time and Routine Index (FTRI), and family adaptation, as measured by the Family Attachment Changeability Index 8 (FACI8). The results also showed a significant positive correlation between parent-child togetherness, as measured by the FTRI, and family adaptation, which suggests a positive relationship between predictable interactions and communication patterns between family members and family resilience.

Similar relationships were found in the study by Bester (2009), who examined resilience in families in which a parent has depression. The results of both the spouse and child subgroups showed a strong and positive statistically significant correlation between family time and routines and family adaptation. Family adaptation and routines that promote couple togetherness, parent child togetherness, and family time together were also positively correlated in both groups. The spouse subgroup identified a significant relationship between family adaptation and routines that promote relative's connection, parent chores routines, and family management routines. However, these results were not found in the child subgroup. The importance of family time and routines was echoed in the regression analysis of the spouses' data, in which family time and routines was identified as a statistically significant predictor of family adaptation.

Similar themes were identified in studies focusing on the burden in family caregivers of dementia patients. Quinn et al. (2008) found that caregivers often develop routines for the care recipients that simplify daily responsibilities and help them to deal with their situation effectively. As the illness progressed, however, the caregivers had to be willing to adjust their coping strategies in order to manage the changing situation

effectively. Zarit (2008) identified daily routines as a buffer to caregiver burden. By employing structured routines, caregivers are better able to deal with dementia-related problems, like inconsistent sleep patterns. Consequently, caregivers reported reduced levels of depression.

3.4.2 Connectedness

People have an intrinsic need to function as separate individuals. As children develop, they gradually learn how to differentiate themselves from others and how to function independently. Family members must learn to accept each other's individual differences and respect each other's need for separateness and boundaries. However, this need for independence is coupled with a need for emotional connectedness or cohesiveness. Cohesiveness, which is often characterised by mutual support, commitment and collaboration, plays a significant role in the resilience process. Healthy families thus learn to balance their degree of connectedness and separateness in an attempt to optimise family functioning (Black & Lobo, 2008; Patterson, 2002b; Walsh, 2003).

When faced with a crisis, families often turn to each other for support. These families might develop or renew their sense of connectedness in an attempt to overcome the difficulties of the situation. The family as a unit takes on a greater priority as the focus of the family's identity moves away from its prior individualistic orientation. Families need to reach a consensus regarding the commitment style that works best for them. There is no ideal amount of emotional connectedness (Patterson, 2002b).

The time a family spends together plays a crucial role in the development of family cohesion. Shared recreation and leisure time promotes attachment, happiness, the development of a sense of humour, learning, and the enjoyment of shared experiences. Family meals and shared family chores uphold continuity and stability in family life. Including all family members in constructive family activities, like housekeeping routines, is also an effective way to reduce time strain and increase family time, which in turn promotes family connectedness (Black & Lobo, 2008).

Ablitt et al. (2009) conducted a systematic review of studies investigating (a) how dementia changes the quality of the relationship between patients and family

caregivers; (b) how the quality of the relationship between family caregivers and dementia patients in the past and in the present affects the ability of caregivers to cope with the experience of living with a dementia patient; and (c) the different relationships between dementia patients and caregivers. Thirty-one peer-reviewed publications that focused on spouses, child-parent caring dyads and mixed groups of family caregivers were included in this review. Most studies found that the current quality of the relationship between the caregiver and the dementia patient had a significant impact on how caregivers experience their role as caregiver. Lower current relationship quality was linked to greater levels of depression, increased strain, and lower perceived self-efficacy in caregivers. In addition, the studies found that current relationship quality influenced the dementia patient in terms of psychological well-being, problem-solving ability and functional ability. However, one study found a relationship between higher levels of current communication quality and higher levels of caregiver distress. Lower communication quality in these caregivers could be explained by the coping strategy they employed, in which they distanced themselves from the dementia patient (Ablitt et al, 2009).

Jonker and Greeff (2009) found that the current relationships between family members also were important in family resilience. In their study of resilience in families with a mentally ill member, 61.8% of the participants identified family characteristics like practical support, emotional support, mutual respect and love for one another as crucial features in the resilience process. These results were echoed in the quantitative results, in which a significant positive correlation was found between family adaptation and the ability of families to work together as a unit when faced with hardship.

This theme was echoed in Preece and Sandberg's (2005) earlier study on family resilience and the effective management of FMS symptoms. They found that marital problems or interpersonal conflict in the family was related to higher levels of family distress, which was significantly correlated with more severe FMS symptoms and increased functional disability in the patient. A good current relationship between family members was thus identified as an important resilience characteristic that helped families to manage FHS symptoms more effectively.

Bester (2009) and Greeff and Wentworth (2009) found that predictable interactions and communication patterns that promote family togetherness were also significantly related to family adaptation. Bester (2009) reported a significant positive correlation between family adaptation and family routines that promote couple togetherness, parent child togetherness and family time together in both the spouse and child subgroups. Data from the spouse subgroup also showed a significant positive relationship between family adaptation and family routines that promote connectedness with relatives. Greeff and Wentworth (2009) also found a significant positive correlation between family adaptation and routines that promote parent-child togetherness.

Losada et al. (2010) found mixed results regarding familial connectedness. The main objective of this study was to analyse the influence of cultural and cognitive variables on depression in family caregivers of dementia patients. The sample used in this study comprised 334 caregivers of relatives with dementia from Madrid and San Sebastian in Spain. Face-to-face interviews, carried out by trained psychologist, were conducted with the caregivers. All of the interviewers were blind to the study objectives. The study focused primarily on the effects of familism, which was defined as the “strong identification and attachment of individuals and their families (nuclear and extended), and strong feelings of loyalty, reciprocity, and solidarity among members of the same family” (p. 194). The results showed that familism was a multidimensional construct, which had both positive and negative effects on caregiver distress. Losada et al. (2010) explain that families with high familism often adhere to rigid views regarding family caregiving, which often lead to dysfunctional thought patterns (e.g. “When a person takes care of a sick relative, he should set aside his interests, and dedicate himself completely to the care of the relative”) (Losada et al., 2010, p. 199). These thought patterns promoted a sense of obligation that not only increased the psychological stress on the caregiver, but also affected relationships with family members who did not adhere to the expected behaviours and attitudes that should be followed according to these rigid views. However, familism also encouraged caregivers to use the family as a reliable source of support, which had an indirect positive effect on caregiver distress.

Ablitt et al.'s (2009) systematic review of studies investigating the different relationships between dementia patients and caregivers revealed that lower relationship quality *prior* to the onset of dementia was also connected to higher levels of strain, burden, depression, psychological distress and emotional reactivity to the challenges of caregiving. On the contrary, caregivers with better prior relationship quality reported better problem solving and communication, more sense of reward and satisfaction, and a higher quality of life. One explanation for this trend was that caregivers who experienced less closeness and intimacy in their prior relationship were more likely to resent their caregiver role. Only one study found no significant relation between the prior relationship quality between the patient and caregiver and the caregiver's morale and mental health. This discrepancy was ascribed to the low levels of mental health problems in the study's sample.

Yamashita and Amagai's (2008) study of the experiences of family caregivers caring for a relative with dementia also found that a good prior relationship between the patient and the caregiver continued on even after the patient was diagnosed with dementia. Participants who reported a good prior relationship with the patient were more likely to accept the illness as part of the ageing process. In contrast, participants who had a poor prior relationship with the dementia patient often believed that problematic behaviours were manifestations of the patient's ill personality and were unable to recognise personality changes brought on by the dementia.

Despite the support found for the protective qualities of good prior relationships between caregivers and patients, Ablitt et al. (2009) found that some studies showed a positive relationship between high levels of past closeness and increased distress in caregivers. One study suggested that this phenomenon might be due to the loss of closeness between caregivers and patients whose prior relationship was characterised by high levels of cohesion.

Mitrani and Czaja's (2000) research on the relevance of interactional patterns as an instrument in the implementation of family-based interventions for family caregivers of dementia patients also mentioned the positive relationship between high levels of past closeness and increased distress in caregivers. They presented the clinical

implications of specific interactional patterns between caregiver-patient dyads using case examples from a clinical trial with white and Cuban American caregivers. They explained that caregivers who were very close to the patient on an emotional or psychological level prior to the diagnosis of the illness often struggled with objectivity with regard to the patient and frequently were unwilling to delegate caregiving tasks, thus making it difficult for them to effectively manage the caregiving system.

3.4.3 Social support

Social networks are key resilience resources. When faced with adversity, resilient families have the strength to admit that they need help. These families are more likely to utilise the available support structures, like extended family, friends, neighbours, faith congregations, community groups and professional services (e.g. counselling). These support systems provide families with practical and emotional support through information, services, companionship, respite, and opportunities to help others and offer them a sense of belonging and cohesion (Black & Lobo, 2008; McCubbin & McCubbin, 1996; Walsh, 2003).

Several studies have discussed the effect of social support on adaptation. Carnes and Quinn's (2005) study of family adaptation to brain injury found that social support, as measured by the F-COPES, was correlated significantly with both increased family functioning and decreased psychological distress. The regression analysis in their study also identified social support as a significant predictor of family functioning. Preece and Sandberg (2005) also identified social support as a vital family resilience component in the management of FMS symptoms. Quinn et al. (2008), who studied the experiences of spouses and co-resident partners of individuals with early-stage dementia, found that having somebody to talk to had a beneficial effect on family caregivers. Furthermore, the buffering role of social support on caregiving distress was supported by the results of the study by Losada et al. (2010), who examined the effect of cultural and cognitive variables on depression in the family caregivers of dementia patients. In addition, an earlier study by Haley et al. (1987) found that higher levels of social support and activity were related to better health outcomes in both dementia caregivers and patients.

Several studies have identified family members and friends as fundamental sources of support that could facilitate the family adaptation process. A statistically significant correlation was found between relative and friend support and family adaptation in the children subgroup in Bester's (2009) study on resilience in families in which a parent has been living with depression. However, no significant correlations were found in the spouse population. In Greeff and Wentworth's (2009) study on adaptation following a heart-related crisis in the family, 83% of the participants identified emotional intra-familial support provided by immediate family as a major feature in the family's adaptation process. The qualitative results in Greeff and Thiel's (2012) study revealed similar results, in that both husbands and wives identified emotional and practical support from family members as the most important internal resilience factor in family adaptation. However, no significant correlations were found in the quantitative data to support these findings.

Haley et al. (1987), who studied the predictors of individual differences in caregiver adaptation, found that caregivers with a larger number of friends and close relationships, and with a greater subjective satisfaction with their social networks, reported higher levels of overall life satisfaction. Higher levels of social activities with friends and church attendance were also significantly correlated with greater life satisfaction. Nonetheless, Quinn et al. (2008) found that social isolation was common in dementia caregivers. Many caregivers found that they were not able to do much without the care-recipient and withdrew from activities and interests. Caregivers increasingly stayed at home and many felt that, as a result of the dementia, they were invited out less by their friends. However, they felt strongly that the informal support from family members and friends was a valuable resource – especially in the early stages of dementia care, during which formal support services were often lacking. Several other studies of factors that buffer burden in dementia caregivers (Losada et al., 2010; Mitrani & Czaja, 2000; Yamashita & Amagai, 2008; Zarit, 2008) emphasised the importance of support from friends and family members.

McCubbin and McCubbin (1996) also emphasised the importance of the community as a social support structure. Community resources that facilitate the family adaptation process include professional services, organisations and social clubs (McCubbin & McCubbin, 1996). Greeff et al. (2006), who examined resilience in

families with a member with a mental disorder, found that the extent to which families experienced support from within the community had a significant correlation with family adaptation in the children subgroup. Although the correlation was not statistically significant for the parents, it did appear important as well. Similar results were found by Greeff and Wentworth (2009), who studied adaptation following a heart-related crisis in the family. The quantitative data showed a significant correlation between family adaptation and the support found by families in the community. In contrast, Yamashita and Amagai (2008) found that seeking help from outside was not in agreement with the societal expectations of families caring for a relative with dementia in Japan. Caregivers believed that, if they made use of external resources, they were abandoning their caregiving responsibility. Community support was thus avoided.

Quinn et al. (2008) identified England's Alzheimer's Society as a beneficial community support resource for dementia caregivers. The Alzheimer's Society provides dementia caregivers with information regarding the illness, which improves their understanding of dementia. Support groups help some caregivers feel less isolated in their role and enables them to make new friends. The caregivers feel comfortable talking to other caregivers about their problems and fears regarding the care-recipient's condition, since they have experience in dementia caregiving and understand the situation. Zarit (2008) also identified voluntary organisations that offer support to dementia caregivers as a helpful coping resource. Zarit (2008) explains that dementia caregivers are often under a great deal of stress when they seek help and often do not ask important questions when put on the spot. That is why support groups or informational sessions by voluntary organisations can be so beneficial. In addition, Zarit (2008) identified paid respite services, like adult day services and in-home carers, as helpful community resources. These programmes assisted family caregivers by taking over a portion of the caregiving responsibilities. This allows family caregivers to carry out other important activities or to take a break, thus decreasing care-related stress, and lowering depression and anger.

Davis (1997) reported a significant relationship between professional services and caregiver burden in a study of family conflict around dementia home-care and the conflict management strategies used by primary family caregivers of dementia

patients. The participants were selected from families in which two or more members who were related to the dementia patient by blood or marriage provided at least four hours of daily, direct, unpaid care for the dementia patient, either individually or collectively. Two semi-structured interviews were conducted with 12 caregivers, who reported high levels of family conflict as measured by the Family Conflict Scale. The study emphasised the important role of physicians, nurses, social workers and other therapists in preparing families to be interdependent, caregiving units. Family counselling, stress management, and family-level skills training in the management of disruptive behaviours were all identified as activities that could alleviate or minimise caregiver burden in those providing long-term homecare for a dementia patient. Family-based psycho-educational interventions on intra-familial communication and the cognitive framing of dementia-related problems were also identified as valuable resources that contribute to increased support from and participation by family members in dementia home-care.

The findings by Davis (1997) regarding professional support was supported by the results of Preece and Sandberg (2005). Preece and Sandberg (2005) suggested marital and family therapy as a fitting treatment approach to help families to manage the problems associated with FMS effectively. According to these authors, professional support could help families to deal with affective disorders and interpersonal relationship problems, which are common in the lives of patients with FMS symptoms. This could facilitate family adaptation. The importance of professional support was echoed by Zarit (2008), who explained that families want to do the best that they can for family members diagnosed with dementia. The support family members receive from physicians and other healthcare providers had a significant effect on the quality of their lives and the quality of care the patient received. The husbands subgroup in Greeff and Thiel's (2012) study on resilience in families with a husband diagnosed with prostate cancer also identified professional support as the second most important coping resource. Greeff and Thiel (2012) point out that medical professionals usually are the family's first source of answers on the illness. Medical information provided by the healthcare team helps families to manage the illness better. Based on the literature, Greeff et al. (2006) also expected a positive relationship between the mobilisation of professional support and family resilience. In the qualitative interviews for their study, several parents mentioned the

mobilisation of help as an important way of coping with a crisis situation. Nonetheless, no significant relationship was found between the mobilisation of professional support and family adaptation. According to Greeff et al. (2006), a possible explanation for this phenomenon is that families get used to the psychological problems related to caregiving, thus gradually reducing the need for professional support.

Jonker and Greeff (2009) obtained mixed results regarding the relationship between social support and family resilience. In their qualitative analysis, 50% of the participants identified social support as an important family resilience factor. However, according to both the quantitative and qualitative analyses, the relationship between family resilience and the family's ability to seek and utilise community resources was relatively insignificant. None of the three social support factors measured by the Social Support Index (SSI) in this study had a significant correlation with family adaptation. Jonker and Greeff (2009) attribute this discrepancy to the study's small sample size, or to possible problems in the statistical analysis. The family's use of friends and relatives as a coping mechanism during crises, as measured by the Relative and Friend Support Index (RFS), was identified as the third strongest predictor of family adaptation, but in a negative direction. This finding was not supported by the literature, the qualitative data, or the Spearman correlations. Greeff and Thiel (2012) also found mixed results regarding social support. Social support – as measured by the Social Support Index (SSI) – had a significant positive relationship with family adaptation in both the husbands' and wives' subgroups. This was echoed in the regression analysis of the husbands' data, which showed that social support was a significant predictor of family adaptation. In contrast, social support as a coping mechanism – as measured by the Family Crisis Oriented Personal Evaluation Scales (F-COPES) – was negatively correlated with family adaptation. Even though these results were not statistically significant, there was a tendency that implied a negative relationship between these variables. Greeff and Thiel (2012) explain that this inconsistency might be due to the nature of the items in the measuring instruments. The Social Support subscale of the F-COPES measures the willingness of families to actively seek social support. The SSI measures the support families received from their community. The two variables should thus be viewed in combination with each other, rather than in isolation, in

order to get a clear picture regarding resilience in families in which a husband has been diagnosed with prostate cancer.

Haley et al. (1996) examined racial differences regarding social support in dementia caregivers. No significant differences were found between black and white caregivers regarding their satisfaction with social support, the total number of social support sources used, the size of their social network, or the total number of visits with relatives and friends. White and black caregivers reported similar changes in their networks as a result of caregiving, and used similar levels of formal help and informal care.

3.4.4 Economic resources

Financial security plays a significant role in family adaptation. Families dealing with poverty potentially have to confront a combination of psychological, social and economic stressors that are beyond their control, like unemployment, a lack of health care, substandard housing, violence, crime and substance abuse. This pile up of stressors could have a negative effect on the emotional well-being and interpersonal relationships of these families. Conversely, good decision-making skills regarding financial management and satisfactory economic status can improve family well-being (Black & Lobo, 2008; Walsh, 2003). Support structures, like affordable eldercare services, affordable health insurance and employment opportunities, are crucial economic resources that facilitate family resilience. However, these resources are only accessible through public programmes and policies. Family resilience should thus be supported by social and institutional policies and practices that focus on these economic resources (Black & Lobo, 2008; Patterson, 2002b).

Carnes and Quinn (2005), who investigated resilience factors related to adaptation in families in which a family member suffered a brain injury, identified financial security as a very strong predictor of family adaptation. This was supported by both the qualitative and quantitative results, which showed a negative relationship between financial security and psychological distress and a positive relationship between financial security and family functioning. In addition, almost half the sample reported concerns regarding insurance coverage, which caused significant psychological distress and lowered family functioning. These findings suggest that insurance

concerns contribute to the pile up of stressors, thus hindering the family resilience process.

Pattanayak et al. (2010) assessed various areas and predictors of dementia caregiver burden in Indian dementia caregivers. A sample of 32 patient-caregiver dyads was recruited from the dementia clinic of a tertiary care hospital in New Delhi, India. Both the patient and the key caregiver were assessed. No relationship was found between caregiver burden and income. However, a significant negative correlation between the education of the caregiver and caregiver burden was reported. This phenomenon may be due to the better skills set obtained by educated caregivers that helps them to deal with stressful situations more effectively, thus leading to a lower perception of burden.

Similar results were found in Greeff et al.'s (2006) study on resilience characteristics in families caring for a member with a mental disorder. In this study, no evidence was found supporting a relationship between family income and adaptation in families dealing with a mentally ill family member. However, a positive relationship existed between the educational level of the parents and family adaptation. No relationships were found between the educational level of the children and the family's adaptation.

Although Greeff and Wentworth (2009) expected a positive relationship between the socioeconomic status of families and family adaptation, no significant correlation was found between these variables in their study on family adaptation following a heart-related crisis. They attribute this finding to the fact that the participants were gainfully employed or made sufficient provision in terms of medical aid schemes, thus enabling them to afford adequate medical services.

3.5 Communication and Problem-solving Processes

Harmonious communication processes encourage cohesiveness and flexibility within family units and play a central role in meaning-making processes, the development of coping strategies, and the preservation of balance and harmony in the family system (Black & Lobo, 2008; Patterson, 2002b). Effective communication processes

can thus foster family resilience by promoting emotional expression, bringing clarity to problem situations, and encouraging collaborative problem solving (Walsh, 2003).

A vital feature that facilitates the family resilience processes is affective communication patterns, through which family members express love and support for each other (Patterson, 2002b). Resilient families engage in open emotional sharing, which is supported by mutual trust, a tolerance for differences, and empathy. However, these families are not immune to negative emotions, and conflict is likely to erupt when emotions are intense. Nonetheless, well-functioning families attempt to listen, understand and respect these emotional outbursts, and to comfort one another when faced with adversity. Families who support each other through these adverse conditions often strengthen their relationship in the process. It should be noted, however, that cultural norms play a significant role in the sharing of sensitive information and the expression of feelings. Gender socialisation, coupled with masculine stereotypes of strength, often restrain men from freely expressing their emotions. Men often avoid showing fear, vulnerability or sadness, and tend to rather withdraw or express anger when faced with adversity. Women, on the contrary, are more likely to express sorrow or anxiety in crisis situations. When family members are unable to share strong emotions with each other, it increases the risk of substance abuse, depression, self-destructive behaviours, relational conflict and estrangement between family members. Mutual trust within a family unit can only prevail if family members feel free to openly express their emotions without shame or judgment (Black & Lobo, 2008; Walsh, 2003).

Several studies of family resilience (Bester, 2009; Greeff & Thiel, 2012; Greeff & Wentworth, 2009; Jonker & Greeff, 2009) have emphasised the importance of open channels of communication in the family adaptation process. These studies identified family problem solving and communication (FPSC Total score) as a very strong predictor of family adaptation during a crisis situation. A significant positive correlation was found between positive, supportive communication patterns, as measured by the Affirming subscale of the FPSC, and family adaptation, as measured by the FACI8. On the contrary, negative, inflammatory communication patterns, as measured by the Incendiary subscale of the FPSC, had a negative

relationship with family adaptation (Bester, 2009; Greeff & Thiel, 2012; Greeff & Wentworth, 2009; Jonker & Greeff, 2009).

Communication patterns that are clear, direct, honest and congruent facilitate effective family functioning. In contrast, unclear, ambiguous communication fosters misunderstandings and confusion, which could lead to mistrust and insecurities within a family unit. Family members attempt to protect one another from threatening or painful information through secrecy or silence. However, family members who are kept in the dark often pick up different bits and pieces of information and frequently fill in the blanks with their worst fears. Sharing and clarifying crucial information regarding a crisis situation (e.g. a poor medical prognosis) play a crucial role in the meaning-making process, which facilitates the decision-making process. Secrecy makes it harder for family members to understand and master the situation and can ultimately lead to estrangement. Shared acknowledgement of the reality, keeping each other informed as the situation develops, and openly discussing questions or concerns regarding adverse conditions, foster healing and facilitate family adaptation (Black & Lobo, 2008; Walsh, 2003).

Zarit (2008) explains that open, clear communication regarding the problems involved in caring for the dementia patient leads to a better understanding of dementia by the whole family and lowers intra-family conflict. Once family members are aware of the patient's problems and how these problems affect the caregiver, they are more willing to increase assistance and support. Research findings show that caregivers who receive more support and assistance from their family experience less of a burden (Zarit, 2008).

Collaborative problem solving and conflict management have been identified as key factors in family resilience. Resilient families recognise problem situations and communicate them openly with everyone involved. Fairness, compassion, understanding and acceptance of differences are crucial during shared decision making and conflict resolution. Members of well-functioning families accommodate one another and tend to avoid criticism, blame and withdrawal during negotiations on problem resolution. Family members openly express their own ideas and encourage all other family members to convey their opinions as well. Once a problem is

resolved, it is important that families reconnect, re-establish a family environment of comfort and security, and maintain a state of equilibrium. During collaborative problem solving, resilient families tend to build on small successes and use failure as a learning experience, thus not only reacting to the problem at hand, but also preparing the family for future clouds on the horizon (Black & Lobo, 2008; McCubbin & McCubbin, 1996; Walsh, 2003).

Mitrani and Czaja (2000), who studied the relevance of interactional patterns as an instrument in the implementation of family-based interventions for family caregivers of dementia patients, describe conflict resolution as a family's ability to successfully resolve differences of opinion without forming destructive coalitions or using intermediaries, while maintaining low levels of negativity within the family unit. They identified several important aspects of conflict resolution that families should work on. Firstly, families should allow differences of opinion and learn how to manage these differences without personal attacks or losing sight of the problem that has to be resolved. Secondly, families should allow the primary caregiver to clearly and directly assert disagreements and/or criticisms, thus allowing painful issues to emerge without reprimand or the loss of relationships. Finally, families should search for adequate solutions that have the support of all the family members involved. Davis (1997) also emphasised the need for families to function effectively as a problem-solving entity when caring for a family member with dementia – especially when practising conjoint caregiving. Conjoint caregiving requires family members to negotiate caregiving activities with each other and to put aside existing differences and disagreements to collaborate in caring for the patient. These families also have to discuss the emotional impact of dementia care and how they collectively can cope with the progression of the illness.

3.6 Individual Characteristics of Family Members

Jonker and Greeff (2009), who conducted a study on resilience in families caring for a family member with a mental illness, found that the characteristics of individual family members could have a positive effect on family resilience. The impact of a single family member's strength on the resilience of the family unit was reported by 67.6% of the participants. Characteristics identified in this category included acceptance, individual perceptions, tolerance, patience, hope, a positive attitude and

perseverance. Greeff and De Villiers (2008) and Greeff and Thiel (2012) also identified the personal characteristics of individual family members as an important factor in the family resilience process.

3.7 Conclusion

This chapter aimed to elaborate on relevant literature that focuses on resilience in families caring for a family member with dementia. However, no studies focusing on this theme were found. The literature search was thus broadened to include family resilience in families caring for family members suffering from other chronic illnesses. Studies on factors that buffer the caretaker burden in families caring for a dementia patient were also included. According to the literature, several factors encourage successful adaptation in families caring for chronically ill family members. Similar factors were found to buffer the caretaker burden in families caring for a dementia patient. These factors included making meaning of adversity; reframing crisis situations to make them more manageable; encouraging optimism; promoting family hardiness; promoting transcendence and spirituality; finding a balance between structure and flexibility; encouraging family connectedness; utilising social and economic support; making use of clear, affirming communication patterns; engaging in shared problem solving; managing the pile up of stressors related to a crisis; and utilising the positive characteristics of individual family members. There were, however, some limitations to these results.

Even though the families mentioned in the family resilience studies faced similar stressors in caring for chronically ill family members, subtle differences exist between the nature of dementia and other chronic illnesses. Some researchers believe that dementia care is a more stressful type of family caregiving and is associated with more negative caregiver implications (Schoenmakers et al., 2010; Schulz & Martire, 2004). Albinsson and Strang (2003) warned that the caregiving environment and its impact on the family might be influenced by these differences. The findings of these studies should thus not be generalised to families caring for dementia patients.

The studies found on dementia care identified several factors that could help buffer the burden of patient care, but these studies never measured the effect of the

identified factors on family adaptation per se. These studies only focused on the burden of the caregiver – a single family member. Even though studies show that individual characteristics of family members have a positive effect on family resilience (Greeff & de Villiers, 2008; Greeff & Thiel, 2012; Jonker & Greeff, 2009), these characteristics are not enough to ensure the adaptation of the family as a unit. Furthermore, none of the studies found on caregiver burden in dementia care was conducted in South Africa. Due to cultural differences, this could have a negative influence on the generalisability of these studies in the South African context.

The literature review thus concludes that there is a large research gap regarding resilience factors in families caring for a dementia patient. Consequently, the aim of the current study was to identify and explore resilience factors that are present in families in which individuals diagnosed with dementia are cared for by their spouses or adult children. Chapter 4 addresses the research design and methodology used in the current study.

CHAPTER 4

METHODOLOGY

4.1 Introduction

Chapter 4 provides a description of the research design and methodology used in the current study. Firstly, the chapter describes the research design employed, followed by a description of the participants in the study and the procedures used to recruit them. The chapter elaborates on the processes and procedures used in the current research and provides a description of the measuring instruments used to collect data. An overview of the data analysis performed on the data gathered is also provided. The chapter concludes with a discussion of the ethical considerations taken into account in this study.

4.2 Research Design

This study focused on family resilience. Since family resilience is a relatively new area of interest, the study was exploratory and descriptive in nature. It was conducted via a cross-sectional survey design, which involved the once-off collection of data from participants in their natural environment in as short a time as feasible (Singleton & Straits, 2010). Data was collected using mixed methods: qualitative data was collected through a semi-structured interview, while quantitative data was gathered via seven self-report questionnaires. A comprehensive description of the measuring instruments used in this study will be provided in Section 4.4.3. In this study, the strength of the relationship between the dependent variable (viz. family adaptation) and several independent variables (viz. family hardiness, coping skills, communication patterns, family time and routines, friend and relative support, and community support) was measured. The study can thus also be described as correlative in nature. However, no cause-and-effect conclusions were inferred in the presence of strong correlations between the variables; the study only attempted to describe the resilience factors present in the target families.

4.3 Participants

4.3.1 Sampling strategy and procedure

The unit of analysis in the current study was the family – a group of two or more people linked through kinship, marriage/domestic partnership, or adoption, who reside in the same household (Nam, 2004). The study thus aimed to identify resilience qualities of the family *as a whole*, and not the individual resilience qualities of a single family member. However, only one family member (chosen by the family unit to act as the family representative) had to be present during the data collection. Due to the sensitive nature of the illness, dementia patients did *not* take part in the data collection process.

A non-probability sampling strategy was used in this study – specifically convenience sampling. Sampling was based on voluntary participation and ethical practices were followed throughout the sampling process. Families who were approached were limited to those in which the spouse or adult child of the dementia patient acted as primary caretaker. Interim analyses determined the final number of families used in the study. Only families who met the following criteria were recruited:

- 1) a family member had been diagnosed with dementia;
- 2) the diagnosis had been made at least one year previously;
- 3) the symptoms of the dementia were moderate to profound;
- 4) the spouse or adult child of the dementia patient acted as the patient's caretaker;
- 5) the person diagnosed with dementia had been living with the family for at least six months; and
- 6) the participant was fluent in either English or Afrikaans.

Two organisations – Dementia South Africa and Alzheimer's South Africa (Western Cape branch) – were approached and asked to help identify possible candidates for this study. Both organisations provide support to families caring for people with dementia. The contact details of these organisations were found on their respective websites (<http://www.alzheimers.org.za> and <http://www.dementiasa.org>) and their

head offices were contacted telephonically to schedule a meeting with an organisation representative. During these meetings, the representatives were provided with a letter from the researcher's supervisor, confirming the details of the study (see Addendum A). The nature and aims of the study were explained to the representatives and they were given a chance to ask questions regarding any remaining uncertainties. The roles that the organisations were willing to play, as well as other concerns regarding ethical considerations, were also discussed. Both Alzheimer's South Africa and Dementia South Africa agreed to help once they had been provided with a research proposal and proof of ethical clearance from the Stellenbosch University Ethics Research Committee (see Addendum B).

Once ethical approval had been obtained from the Stellenbosch University Ethical Research Committee, Dementia South Africa and Alzheimer's South Africa were provided with proof of ethical clearance. Both organisations invited the researcher to attend their monthly family support groups. The organisations contacted their support group organisers via e-mail, explaining the nature and aims of the study and requesting their assistance. The contact details of the support group organisers who were willing to help with recruitment were forwarded to the researcher. These support group organisers were contacted telephonically, at which time a date was scheduled on which the researcher could attend a meeting. A specific slot during the meeting was allocated to the researcher in which she was allowed to discuss the study. The organiser of the support group introduced the researcher and members who were not interested in the study were allowed to leave before the researcher addressed the group. The researcher was given a chance to explain the aims and nature of the study to the group members and their assistance was requested. A form that provided a short description of the study was sent around the room and group members who were willing to participate in the study were asked to fill in their contact details (see Addendum C). In addition, Dementia South Africa posted a flyer advertising the study on their Facebook page (see Addendum D). Alzheimer's South Africa also agreed to contact their members via post or e-mail to explain the details of the study to them. The participating organisations did not provide the researcher with the contact details of any of their members unless those members gave them permission to do so.

Groote Schuur Hospital and Panorama Memory Clinic – which both specialise in the field of memory and dementia care in the Western Cape – were also approached and asked for assistance in identifying possible participants. Their assistance was requested via e-mail and a meeting was scheduled with hospital representatives to discuss the research. The representatives of the two hospitals were provided with the research proposal and proof of ethical clearance from the Stellenbosch University Ethics Research Committee. Once again, the nature and aims of the study were explained to the representatives and they were given a chance to ask questions regarding any remaining uncertainties. The representatives of both medical facilities agreed to assist in the recruitment of possible participants (see Addendum B). Panorama Memory Clinic invited the researcher to attend their monthly support group meetings. The same procedure followed at the Dementia South Africa and Alzheimer's South Africa support groups were followed at Panorama Memory Clinic's support group. Flyers advertising the research study (see Addendum D) also were displayed in the waiting room at Panorama Memory Clinic. Groote Schuur Hospital invited the researcher to attend their weekly Geriatrics Clinic and Memory Clinic. Medical staff approached the family members who accompanied dementia patients and asked them whether they would be willing to participate in a study on the families of dementia patients. If the families agreed, a hospital staff member introduced the researcher to the participants. Data was then collected at the hospital.

4.3.2 Demographics of participants

During the recruitment process, 118 individuals volunteered to participate in this study. However, 27 volunteers had to be excluded because (a) the dementia patient was deceased at the time of data collection; (b) the dementia patient did not reside in the same household as the volunteer; or (c) the primary caregiver of the dementia patient was not the spouse or an adult child. Of the families identified, 91 participated in the study. The participating families were divided into two groups – families in which the spouse of the dementia patient took on the role of primary caregiver ($n = 44$) and families in which the adult child of the dementia patient took on the role of primary caregiver ($n = 47$). Data was collected from a single family member chosen by the family unit to act as the family representative. Of the 91 families participating

in this study, 59% (n = 54) were coloured, 30% (n = 30) were white, 5% (n = 5) were black, and 2% (n = 2) identified themselves as “Other”. The home language of the participating families was mostly English (n = 51; 56%), followed by Afrikaans (n = 35; 38.5%) and Other (n = 5; 5.5%). According to the Bureau of Marketing Research (2012), 48% of the households in South Africa earned less than R50 000 a year (R4 166.66 a month) in 2010. Conversely, 31.3% of South African households earned more than R100 000 annually (R8 333.33 a month) in 2010. Similar income distributions were found in the current study’s population group. The household income of the families was as follows: 12% (n = 13) earned between R1 001 and R2 000 a month; 31% (n = 28) earned between R2 001 and R5 000 a month; 16% (n = 14) earned between R5 001 and R10 000 a month; 16% (n = 14) earned between R10 001 and R15 000 a month; and 24% (n = 22) earned more than R15 000 a month. Most families listed two adults (n = 30; 33%) or three adults (n = 30; 33%) living together in the household. Thirteen families (14%) had four adults living in the same household; 15 families (16%) listed five adults in the household; and three families (3%) had more than five adults in the household. Most families (n = 55; 60%) had no children under 18 living with them.

Of the family representatives in this study, 52% were the adult children, children-in-law or grandchildren of the patient, while 48% of the participating families were represented by the spouse of the patient. Most family representatives were female (n = 67; 74%). The family representatives were aged between 20 and 90, with a mean age of 59.0 (SD = 15.5). The majority of the family representatives were married (n = 69; 76%). The rest were either single (n = 12; 13%), cohabiting (n = 3; 3%), divorced (n = 4; 4%), or widowed (n = 2; 2%). One family representative listed “Other” as marital status. Forty families who participated in this study lived with a male patient (44%), while 51 families lived with a female patient (56%). The majority of the patients were diagnosed with Alzheimer’s disease (n = 48; 53%) or vascular dementia (n = 22; 24%). Fourteen participants (15%) were unsure what the final diagnosis of the patient was. The patients were aged between 50 and 90, with a mean age of 75.8 (SD = 8.8). In this study, 24 patients (26%) had been diagnosed with dementia one to two years previously, 31 patients (34%) had been diagnosed with dementia two to four years previously, 26 patients (29%) had been diagnosed

with dementia four to six years previously, and 10 patients (11%) had been diagnosed more than six years previously.

4.4 Measures

The participants were asked to (1) fill out a biographical questionnaire; (2) answer three open-ended questions regarding factors that contributed to the family's adaptation; and (3) complete seven quantitative self-report questionnaires.

4.4.1 Biographical questionnaire

Biographical information was collected with structured questions regarding home language, socioeconomic status, marital status, family composition, the age and gender of the dementia patient, and information regarding the onset and duration of the illness (see Addendum E).

4.4.2 Qualitative measure

Qualitative data was collected via a semi-structured interview with the family representative. In the interview, the following open-ended questions were posed to the participants:

- 1) 'In your own words, which family characteristics helped your family adapt to caring for a family member who is diagnosed with dementia?';
- 2) 'In your own words, what social, financial and community resources helped your family adapt to caring for a family member who is diagnosed with dementia?'; and
- 3) 'What advice would you give other families who have to care for a family member diagnosed with dementia?'

In some cases the participants elaborated on social, financial and community resources while answering the first question. In these cases, the second question was left out and the interviewer proceeded to the third question. Qualitative data collection for each subgroup only continued until data saturation was reached ($n = 40$). The participating families were interviewed on a first come, first served basis.

Once data saturation was reached, qualitative data collection was terminated and the subsequent participants who fell into the saturated subgroup were only asked to complete the quantitative measures.

4.4.3 Quantitative measuring instruments

In an attempt to identify the factors that facilitate the adjustment and adaptation of families caring for a family member who is diagnosed with dementia, the participants were asked to complete seven self-report questionnaires. The questionnaires were selected based on previous research regarding family resilience and are in accordance with McCubbin and McCubbin's (1996) Resiliency Model. The Family Attachment Changeability Index 8 (FACI8) was used to measure the dependent variable in this study – family adaptation. The independent variables were measured using the Family Crisis Oriented Personal Evaluation Scales (F-COPES); the Family Hardiness Index (FHI); the Family Problem Solving and Communication Scale (FPSC); the Family Time and Routine Index (FTRI); the Relative and Friend Support Index (RFS); and the Social Support Index (SSI). This study formed part of a larger study conducted by Prof. A. P. Greeff, who obtained the necessary permission from the intellectual property holders to use these questionnaires. All measuring instruments used were available in both English and Afrikaans. A translation-back-translation procedure was followed in the translation of these questionnaires into Afrikaans.

4.4.3.1 Family Attachment Changeability Index 8 (FACI8)

The Family Attachment Changeability Index 8 (FACI8) was used to measure the dependent variable in this study – family adaptation. This index was adapted by Hamilton McCubbin, Anne Thompson and Kelly Elver from the *Family Adaptability and Cohesion Evaluation Scales* (FACES). It consists of 16 items that respondents rate on a five-point Likert scale based on how applicable the statements are to their family. Responses on these scales range from “Never” = 1 to “Always” = 5. The FACI8 consists of two subscales: (1) the *attachment* subscale and (2) the *changeability* subscale. The attachment subscale measures the level of family cohesion, and the changeability subscale measures the level of family flexibility. If completed by an adult, the internal reliability (Cronbach's alpha) of the attachment

subscale and the changeability subscale is .75 and .78 respectively. Both subscales have a test-retest reliability of .48 (McCubbin, Thompson & Elver, 1996f). The FACI8 obtained an overall internal reliability (Cronbach's alpha) of .67 in the current study, whilst the subscales attachment and changeability obtained an internal reliability of .65 and .76 respectively.

4.4.3.2 Family Crisis Oriented Personal Evaluation Scales (F-COPES)

The Family Crisis Oriented Personal Evaluation Scales (F-COPES), developed by Andrea Larsen, Hamilton McCubbin and David Olson, was used to identify the problem-solving and behavioural strategies families use when faced with hardship. The F-COPES consists of 30 items rated on a five-point Likert scale ranging from "Strongly disagree" = 1 to "Strongly agree" = 5. The scale consists of five subscales that are divided into two dimensions, namely (1) *internal coping skills* – measuring the extent to which crises are managed by using resources within the nuclear family system; and (2) *external coping skills* – measuring the extent to which the family manages crises outside its boundaries by eliciting support from the community. Internal coping skills include (1) *reframing* the situation to make it more manageable and (2) *passive appraisal*, in which families accept the situation and minimise their reactivity towards it. The Cronbach's alphas of these subscales are .82 and .63 respectively, and their test-retest reliability is .61 and .75 respectively (McCubbin, Olson & Larson, 1996d). External coping strategies include (1) acquiring *social support* from relatives, friends, neighbours and extended family, (2) seeking *spiritual and religious support*, and (3) the *mobilisation* of family members to seek and accept help from others. The Cronbach's alphas of these subscales are .83, .80, and .71, while the test-retest reliabilities of these subscales are .78, .95 and .78 respectively (McCubbin et al., 1996d). The internal reliability coefficient (Cronbach's alpha) is .86 for the whole scale, and the test-retest reliability is .81 (McCubbin et al., 1996d).

In the current study, the reframing and passive appraisal subgroups obtained an internal reliability (Cronbach's alpha) of .70 and .64 respectively. The social support subscale had an internal reliability (Cronbach's alpha) of .79, the spiritual and religious support subscale had an internal reliability (Cronbach's alpha) of .77, and the mobilisation subscale had an internal reliability of .66. In this study, the F-COPES attained an overall internal reliability (Cronbach's alpha) of .79.

4.4.3.3 Family Hardiness Index (FHI)

The Family Hardiness Index (FHI), which was developed by Hamilton McCubbin, Marilyn McCubbin and Anne Thompson, was used to measure the internal strength and durability in the family unit when confronted with a crisis situation. The FHI consists of 20 items in which respondents have to indicate to which extent the statement is applicable to their current family situation, using a five-point Likert scale. The responses range from “False” to “True”. If the item does not apply to the family situation of the respondent, the “Not applicable” option should be marked. Items are divided into three subscales: (1) *commitment*, (2) *challenge* and (3) *control*. The commitment subscale measures the family’s dependability, sense of internal strengths, and ability to work together. The challenge subscale measures the family’s efforts to positively reframe crises, learn new things, be innovative, and actively seek out new experiences. The control subscale measures the family’s perception of control regarding their own life. The internal reliability (Cronbach’s alpha) of the FHI (total scale) is .82; the test-retest reliability is .86; and the validity coefficient ranges from .20 to .23 when correlated with family flexibility, satisfaction, time, routine and adaptability variables (McCubbin, McCubbin & Thompson, 1996b). An overall internal reliability (Cronbach’s alpha) of .72 was obtained by the FHI in the current study. The commitment, challenge and control subscales obtained in this study had internal reliabilities (Cronbach’s alpha) of .71, .67 and .56 respectively.

4.4.3.4 Family Problem Solving and Communication (FPSC) Index

The Family Problem Solving and Communication (FPSC) Index was used to measure the positive and negative communication patterns the families used during stressful situations that influenced problem solving and coping (McCubbin et al., 1996c). The scale consists of 10 items on a four-point Likert scale ranging from “False” = 0 to “True” = 3. The scale, which was developed by Hamilton McCubbin, Marilyn McCubbin and Anne Thompson, is divided into two subscales. The positive communication subscale, referred to as ‘Affirming Communication’, represents positive communication patterns that convey support and care and serve to calm a situation. The negative communication subscale, known as ‘Incendiary Communication’, represents negative communication patterns that are provocative and tend to intensify a stressful situation. The FPSC has an overall internal reliability

(Cronbach's alpha) of .89 and a test-retest reliability of .86. The incendiary communication subscale has an internal reliability (Cronbach's alpha) of .78, while the affirming communication subscale has an internal reliability (Cronbach's alpha) of .86 (McCubbin et al., 1996c). In the current study, the FPSC had an overall internal reliability of .88. The incendiary communication subscale and the affirming communication subscale had an internal reliability of .74 and .88 respectively.

4.4.3.5 Family Time and Routine Index (FTRI)

The Family Time and Routine Index (FTRI), also developed by Marilyn McCubbin, Hamilton McCubbin and Anne Thompson, was used to evaluate the types of activities and routines families engage in, and the value they attribute to these practices. The scale consists of 30 items that respondents rate on two four-point Likert scales. On the first scale the respondents are asked to rate how applicable statements are to their family currently, with responses ranging from "False" = 0 to "True" = 3. On the second scale, they are asked how often they would like the item to occur in their family, with responses ranging from "Not important" to "Very important", with "Not applicable" being the fourth option. The FTRI has eight subscales in total: (1) *Parent-child togetherness* – measuring the family's emphasis on predictable communication between parents and children; (2) *Couple togetherness* – which assesses the family's emphasis on creating routines to encourage communication between spouses; (3) *Child routines* – indicating the family's emphasis on creating predictable routines to promote children's sense of independence and order; (4) *Meals together* and (5) *Family time together* – measuring the family's emphasis on predictable routines to encourage togetherness; (6) *Family chores routines* – which assesses the family's emphasis on establishing predictable routines; (7) *Relatives connection routines* – measuring the family's attempts to create predictable routines to encourage a meaningful connection with relatives; and (8) *Family management routines* – indicating the family's attempts to create predictable routines to promote an atmosphere of family organisation and the accountability necessary to uphold family order in the home. The FTRI has an internal reliability of .88 (Cronbach's alpha), and validity coefficients ranging from .19 to .34 when correlated with measures of family bonding, family satisfaction, marital satisfaction, family celebrations and family coherence (McCubbin, McCubbin & Thompson, 1996a).

In this study, the internal reliability (Cronbach's alpha) of the FTRI (total scale) was .96. The internal reliability of the subscales in the current study were as follows: the Importance attributed to family time and routines subscale obtained a Cronbach's alpha of .97; the Parent-child togetherness subscale obtained a Cronbach's alpha of .91; the Couple togetherness subscale obtained a Cronbach's alpha of .80; the Child routines subscale obtained a Cronbach's alpha of .95; the Meals together subscale obtained a Cronbach's alpha of .78; the Family time together subscale obtained a Cronbach's alpha of .59; the Family chores routines subscale obtained a Cronbach's alpha of .88; the Relatives connection routines subscale obtained a Cronbach's alpha of .64; and the Family management routines subscale obtained a Cronbach's alpha of .84.

4.4.3.6 Relative and Friend Support Index (RFS)

The Relative and Friend Support Index (RFS), developed by Andrea Larsen, Hamilton McCubbin and David Olson, was used to measure the degree to which families make use of friend and relative support to help them cope when faced with stressors (McCubbin, Thompson & McCubbin, 1996g). The scale consists of eight questions asking respondents to rate, on a five-point Likert scale ranging from "Strong disagreement" = 1 to "Strong agreement" = 5, the extent to which the family shares problems and asks for advice from friends and relatives. The RFS has an internal reliability (Cronbach's alpha) of .82 and a validity coefficient of .99 when correlated with the original Family Crisis Oriented Personal Evaluation Scales (McCubbin et al., 1996g). The internal reliability (Cronbach's alpha) of the RFS in this study was .76.

4.4.3.7 Social Support Index (SSI)

The Social Support Index (SSI), developed by Thomas Glynn, Hamilton McCubbin and Joan Patterson, was used to determine the extent to which the participating family (1) has integrated into their community; (2) finds support in their community; and (3) makes use of community resources for emotional, esteem and network support (McCubbin, Patterson & Glynn, 1996e). It consists of 17 items rated on a five-point Likert scale, with responses ranging from "Strongly disagree" = 0 to "Strongly agree" = 4. The SSI's internal reliability (Cronbach's alpha) is .82, the

validity coefficient is .40 when correlated with a measure of family well-being, and the test-retest reliability is .83 (McCubbin et al., 1996e). In the current study, the SSI had an internal reliability of .80.

4.5 Procedure

Before the current study could commence, ethical approval had to be obtained from the Stellenbosch University Ethical Research Committee. Once the research was approved, families who fit the research criteria were asked to participate. The data collection process took place over a period of approximately seven months – from February 2012 until August 2012. Three recruitment methods were used to obtain volunteers for the study: (1) recruitment at Groote Schuur Hospital's Memory Clinic and Geriatrics Clinic; (2) recruitment through dementia support groups; and (3) recruitment through pamphlets advertising the study.

In an attempt to recruit volunteers for the current study, the researcher attended Groote Schuur's weekly Memory Clinic and Geriatrics Clinic. Hospital staff members introduced the researcher to the family members of dementia patients who fit the research criteria and who were willing to participate in the study. Upon introduction, the researcher briefed the interested families on the nature of the study, the study's data collection methods, the estimated time frame of the study, and the possible risks of the study. The researcher provided the families with a written consent form that covered all relevant information regarding the study (see Addendum H) and explained all the main points discussed in the form. The families were given a chance to ask questions regarding any uncertainties. If they still agreed to participate, they had to choose a family member to act as family representative, and who had to complete all the data collection measures. Family representatives had to sign the written consent form as proof that they were willing to participate voluntarily. Participants who were part of the qualitative data collection process then followed the researcher to a private room in the hospital where the interviews were conducted. Families who only had to complete the quantitative measures were allowed to complete the questionnaires in the waiting room and did not have to meet with the researcher privately.

The support group leaders of Dementia South Africa, Alzheimer's South Africa and Panorama Hospital invited the researcher to attend their monthly family support groups in the Cape Metropolitan area. The organiser of the support group introduced the researcher to the group, after which the researcher was given a chance to discuss the nature of the study, the study's data collection methods, the estimated time frame of the study, and the possible risks of participation in the study. Members who were not interested in the study were allowed to leave before the researcher addressed the group. A form requesting assistance from volunteers was sent around the room and group members who were willing to participate in the study were asked to fill in their contact details (see Addendum C). The researcher contacted the interested candidates telephonically and once again briefed them on the details of the study. If they agreed to participate, an appointment was scheduled at a time and place that was convenient for the participant. On arrival at the appointment, the researcher thanked the participants for agreeing to participate in the study and handed them a written consent form that covered all relevant information regarding the study (see Addendum G). The content of the consent form was explained to them in detail and they were asked to sign the form (see Addendum H) if they still showed interest in the study. The family then had to pick a family representative to complete all the data collection measures.

Flyers advertising the study were also used as a recruitment measure (see Addendum D). The flyers contained a short description of the study and only highlighted the most important information. Dementia South Africa posted a flyer on their Facebook page. These flyers were also displayed in the waiting room at the Panorama Memory Clinic. The contact details of the researcher were included on the flyers and families who were willing to participate were able to contact the researcher telephonically or via email. The details of the study were explained to the volunteers and an appointment was scheduled at a time and place that was convenient for the participants if they agreed to participate. The same procedure that was followed during the appointments with participants recruited from the support groups was followed in this group.

The appointments, during which data was gathered, lasted between 30 and 120 minutes. The participants who were recruited at Groote Schuur Hospital completed

the data collection session at the hospital. The researcher met most other participants at their residences. Three participants preferred meeting at a coffee shop and two participants met the researcher at their place of employment. The voluntary nature of participation was emphasised during all the appointments. The anonymity and confidentiality of the participants were also assured and the researcher explained to the participants how their identities would be safeguarded. During this conversation, the participants were allowed to ask questions about any uncertainties regarding the study. Once the participants gave their consent (and signed the consent form), they were asked to complete a biographical questionnaire (see Addendum E). This was followed by a semi-structured interview in which the family representatives were asked to elaborate on the family resilience resources they utilised that helped their family unit adapt to their current situation. The researcher probed the participants for more in-depth answers when necessary. The participants were encouraged to be truthful and to use their personal experiences when answering. All the interviews were recorded digitally. However, only a limited number of participants were interviewed. Once sufficient qualitative data was obtained (saturation), the remaining participants were not asked to complete the qualitative measure. In the final step of data collection, the participants had to complete the seven quantitative questionnaires (discussed in Section 4.3.3) in the presence of the researcher. They were encouraged to ask questions if they did not understand anything. Once the participants had completed the questionnaires, they were thanked for their participation. They did not receive any monetary compensation. All the participants were informed that the general results of the study would be available to them via email on request, but that no individual feedback would be given. The results would also be made available to the organisations that were willing to assist in identifying possible participants.

Once data collection had been concluded, all the responses were entered into a pre-developed Microsoft Excel spreadsheet and scored according to established formulae. Numerical values were assigned to the responses to the biographical questionnaire, which facilitated the data entry and ultimately the statistical analyses. Statistical analyses commenced once all the data was entered into the Microsoft Excel spreadsheet.

4.6 Data Analysis

4.6.1 Quantitative data analysis

The quantitative data analysis was carried out in partnership with a senior statistician at the Statistical Consultation Service of Stellenbosch University. The data was analysed using Statistica (Statsoft Incorporated, 2011). Firstly, an analysis of variance (ANOVA) was performed to determine whether any significant differences occurred between the identified subgroups in terms of both the dependent variable and the independent variables. Secondly, the strength and direction of the relationships between the dependent variable and the independent variables were determined by calculating Pearson's product-moment correlation coefficients. A .05 probability level was used to determine the significance of the correlation coefficients. The correlation coefficients of the spouse and child subgroups were explored separately to determine whether any significant differences were evident regarding the prevalence of resilience factors in the families of these two groups. Finally, the combination of independent variables that best predicted the value of the dependent variable was determined in both the spouse and child subgroups by conducting a multiple regression analysis. The independent variables included in the multiple regression equation were established using a best-subsets regression analysis.

4.6.2 Qualitative data analysis

The aim of a qualitative data analysis is to generate a detailed, systematic recording of the themes and categories identified in interviews. This study used a thematic analysis approach to accomplish this. In this study, the interviews were recorded digitally and saved, transcribed and analysed using a password-protected personal computer. The interviews of the Afrikaans-speaking participants were translated into English by the researcher. The transcripts were read repeatedly and statements were labelled and categorised according to their content. To ensure that the categories were mutually exclusive and exhaustive, similar categories were grouped together and overarching categories were merged. The identified categories represented factors contributing to family resilience and the raw data was encoded according to these categories. The findings were then written up alongside references to the literature. The original copies of the transcripts were saved to

ensure that the contexts of the coded sections were maintained (Braun & Clarke, 2006; Burnard, 1991).

4.6.3 Trustworthiness

Guba (cited in Shenton, 2004) described four basic constructs that could enhance the trustworthiness of a study: (1) credibility, (2) Fde transferability, (3) dependability, and (4) confirmability.

Credibility, defined as the congruency between the findings of the study and reality (Shenton, 2004), was enhanced by gathering both qualitative and quantitative data from the same unit of analysis, i.e. the family (triangulation). Using both interviews and questionnaires allowed for the comparison and validation of the results. In addition, only participants who were willing to participate were recruited. The qualitative questions were posed before the quantitative measurements were administered to ensure that the responses of the participants were not influenced by the themes addressed in these questionnaires. In addition, the researcher made use of probing during qualitative data collection to elicit more detailed answers from the participants. Furthermore, credibility was enhanced through: (a) frequent debriefing sessions with a skilled supervisor throughout the study; (b) the validation of findings by comparing the results of the current study with prior research findings; and (c) an in-depth description of the constructs and participants that were studied (Shenton, 2004).

Transferability refers to the extent to which the findings of the study can be applied to other situations (Shenton, 2004). In this study, an in-depth description of the data collection procedure was given to ensure that the future researchers fully understood the context in which this study commenced. In addition, participants were asked to complete a demographic questionnaire. By describing the demographic characteristics of the participants, the degree to which the findings could be transferred to other population groups was enhanced.

Dependability addresses the issue of reliability – the extent to which similar results would be obtained should the study be replicated (Shenton, 2004). The research

design and data collection and analysis methods employed in this study were described in detail to ensure that the research could be replicated in future studies.

Confirmability is the comparable concern a researcher shows regarding the objectivity of a study (Shenton, 2004). Researchers need to acknowledge the influence of their own backgrounds, experiences and beliefs on the data collected. In this study, this was done through constant self-reflexivity by the researcher, in which the researcher's own predispositions were under scrutiny. Confirmability was also pursued via peer debriefing. Three transcripts were given to two postgraduate students of Stellenbosch University who were familiar with thematic analysis, but were not involved in any aspect of this study. They were asked to read the transcripts and their opinions regarding emerging themes were discussed. The themes identified through peer debriefing were compared and integrated into the themes identified by the researcher.

4.7 Ethical Considerations

To ensure that no human rights violations occurred during this study, three main ethical principles were upheld: (1) ensuring the personal safety of the participants; (2) emphasising informed consent; and (3) respecting the participants' right to privacy (Holloway, 1997; Singleton & Straits, 2010).

All research participants have a right to personal safety and researchers need to ensure that the participants' physical well-being, psychological well-being and human dignity are preserved (Holloway, 1997; Singleton & Straits, 2010). In this study, there were no risks involved regarding the physical well-being of the participants. However, caring for a family member suffering from dementia could be strenuous on the psyche of an individual and extra precaution had to be taken to ensure that no psychological pain resurfaced during data collection. The researcher emphasised that the participants were allowed to withdraw from the study if they felt that they were unable to continue. The researcher also reminded them that they were free to choose which private information they wanted to disclose and that they had the right to refuse to answer a question. In addition, the study focused on the resources and characteristics that help families to make the necessary changes to adapt and continue with their lives. The participants thus were encouraged to be positive and to

think about their strengths, which could prove to be a therapeutic exercise. The researcher provided all participants with the contact details of Prof. A. P. Greeff – a psychologist who would have helped them free of charge if they experienced any psychological distress after meeting with the researcher. The contact details of two other psychologists were also provided for those individuals who preferred a professional in private practice. In addition, all the participants were given the contact details of FAMSA – an organisation dedicated to the development of functional family relations. Once all the data was collected, the session was concluded with a short discussion in which the participants were allowed to express their feelings about the study. None of the participants reported any grievances. To ensure that the dignity of the participants was preserved, all participants were treated with respect and courtesy throughout the research process.

All research subjects should be allowed to make an informed decision on whether they want to participate in the study or not (Holloway, 1997; Singleton & Straits, 2010). The details of this study were explained in detail to the families that were willing to participate and they were given a chance to ask questions regarding any uncertainties. It was emphasised that participation in the study was voluntary and that they could withdraw from the study at any time without fear of negative repercussion. Once the participants were fully briefed, they were asked to read and sign a consent form (see Addendum G).

Research participants also have the right to privacy, anonymity and confidentiality as far as practicable (Holloway, 1997; Singleton & Straits, 2010). All data collected in this study was treated as confidential. However, since data collection entails a face-to-face meeting between the participant and the researcher, absolute anonymity was not possible. In an attempt to maintain anonymity and confidentiality, the participants were identified through a randomly assigned number written on all the measuring instruments completed by that participant. The digital recording of the participant's response to the qualitative questions was also saved under the participant's assigned number. No information that could later link the data to the participants was recorded on any of the measuring instruments, and no records that linked the names to the corresponding numbers were kept. The identity of the families who agreed to participate in the study was also kept confidential and was only known by the

researcher, who was also the only one conducting the interviews. The digital recordings of the qualitative interviews, the typed transcripts, and all other data coded virtually were stored on a password-protected personal computer that was only used by the researcher. The data was also stored on a password-protected flash drive as backup. The flash drive and questionnaires completed by the participants were stored in a locked drawer at the researcher's residence. The data will be kept until 2017. In addition, no details that could link a participant to the study were disclosed in the reporting of the results.

CHAPTER 5

RESULTS

5.1 Introduction

Chapter 5 elaborates on the results obtained in the current study, which focused on resilience qualities of families living with a family member diagnosed with dementia. Firstly, the results concerning the demographics of the participants will be discussed. Secondly, the results of the analysis of variance (ANOVA) of the spouse subgroup ($n = 44$) and the child subgroup ($n = 47$) regarding both the dependent variable and the independent variables will be reported. Any statistically significant mean differences identified between the subgroups will be presented visually as well. Subsequently, the Pearson's product-moment correlation coefficients, which represent the strength and direction of the relationships between the dependent variable and the independent variables, will be reported. The results of the multiple regression analyses, which identify the combination of independent variables that best predict variances in the dependent variable, will follow. Finally, the results of the qualitative data analysis will be reported.

5.2 Demographic Results

In an attempt to improve the validity of the results of the current study, the participants were asked to complete a demographic questionnaire (see Addendum E). By describing the demographic characteristics of the participants, the degree to which the findings could be transferred to other population groups was enhanced, thus increasing transferability.

The influence of demographic differences on the results was controlled for by performing an analysis of variance (ANOVA) on the FACI8 scores of the different demographic subgroups. The only variable that showed a significant difference between subgroups was the gender of the patient. Families caring for male patients obtained higher FACI8 scores, $F(1, 89) = 5.06$, $p = .03$, thus implying better family adaptation in families from this subgroup. The gender of the caregiver also seemed to be associated with family adaptation. Families in which females acted as the

primary caregiver tended to obtain higher FACI8 scores, $F(1, 89) = 3.53$, $p = .06$. However, this result was not statistically significant.

The Spearman correlation coefficients between family adaptation (as measured by the FACI8) and several demographic variables were calculated to determine whether any of these variables had a significant relationship with family adaptation. The results obtained are presented in Table 5.1.

Table 5.1

Spearman's Correlation Coefficients Found Between the Demographic Variables and the Level of Family Adaptation as Measured by the FACI8 (N = 91)

Variable	Spouse (n = 44)		Child (n = 47)	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Family income	.09	.55	.37	.01**
Number of adults in household	.19	.22	.33	.03*
Number of children in household	-.13	.39	-.11	.45
Level of education of primary caregiver	-.11	.50	.16	.29
Age of primary caregiver	-.31	.04*	.00	.99
Age of patient	-.39	< .01**	-.18	.23
Number of years since diagnosed	-.05	.75	-.04	.79

* $p \leq .05$

** $p \leq .01$

The results revealed that household income had a significant positive relationship with family adaptation in the child subgroup ($r = .37$, $p = .01$). This correlation implies that families with a higher household income tend to be better adapted than families with lower household incomes. However, these results were not found in the spouse

subgroup. The number of adults in the household also had a statistically significant, positive relationship with family adaptation ($r = .33$; $p = .03$) in the child subgroup. This relationship was not found in the spouse subgroup either. The only factors that were correlated significantly with family adaptation in the spouse subgroup were the age of the patient ($r = -.39$; $p < .01$) and the age of the primary caregiver ($r = -.31$; $p = .03$). These variables were not significantly correlated with family adaptation in the child subgroup.

5.3 Quantitative Data

5.3.1 Analysis of variance (ANOVA)

One of the aims of the current study was to identify possible differences in family resilience qualities between families in which spouses and adult children care for a dementia patient. In an attempt to identify whether these subgroups differed significantly in terms of their families' adaptation, an analysis of variance (ANOVA) was performed comparing their FACI8 scores. The results of this ANOVA are depicted in Figure 5.1.

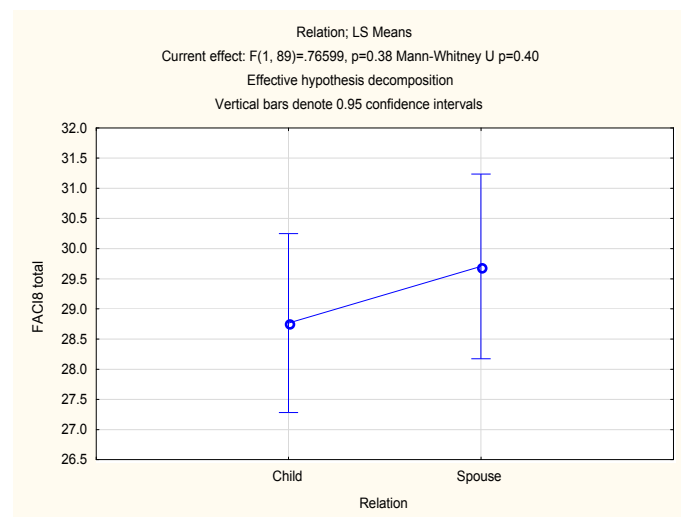


Figure 5.1 ANOVA: Results Obtained on the Total Score of the FACI8.

As can be seen in Figure 5.1, no significant difference was found between spouses and adult children caring for a family member with dementia in terms of family adaptation (as measured by the FACI8), $F(1, 89) = 0.77$, $p = .38$. Even though the families' levels of adaptation did not differ, the extent to which the families utilise

different potential resilience resources to help them adapt might differ. Consequently, various analyses of variance (ANOVAs) were conducted. Statistically significant differences were found for three variables: community support and the utilisation of community resources (SSI: Total); overall problem-solving communication patterns (FPSC: Total); and affirming communication patterns (FPSC: Affirming Communication). The results of the ANOVA on the total score of the SSI are presented in Figure 5.2.

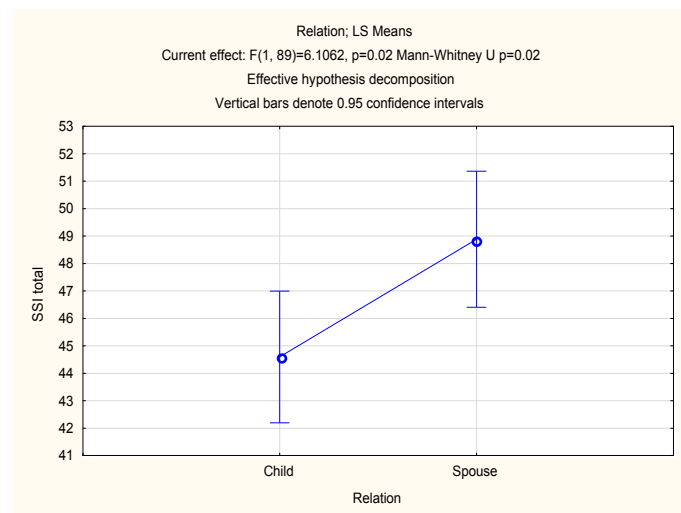


Figure 5.2 ANOVA: Results Obtained on the Total Score of the SSI.

Firstly, a significant difference in the total scores of the SSI was found between the spouse subgroup and the child subgroup, which shows that the spouse subgroup obtained significantly higher scores than the child subgroup, $F(1, 89) = 6.11$, $p = .02$. This implies that families in which spouses took on the role of caregiver more often made use of community resources as a support system than families in which children were the caregivers of their parents diagnosed with dementia. The results of the ANOVA on the total score of the FPSC are presented in Figure 5. 3.

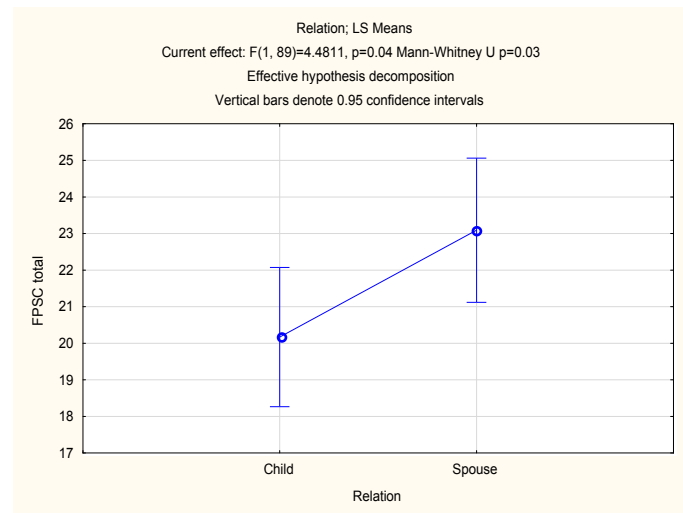


Figure 5.3 ANOVA: Results Obtained on the Total Score of the FPSC.

Figure 5.3 shows a significant difference in the total FPSC scores between these groups, $F(1, 89) = 4.48, p = .04$. The spouse subgroup obtained a higher total score in the FPSC than the child subgroup, which suggest that families in which spouses are the primary caregivers of dementia patients more often made use of healthier communication patterns that influence problem solving and coping during stressful situations. These findings were supported by the results of the ANOVAs on affirming communication patterns (FPSC: Affirming Communication) and incendiary communication patterns (FPSC: Incendiary Communication), as seen in Figure 5.4 and Figure 5.5.

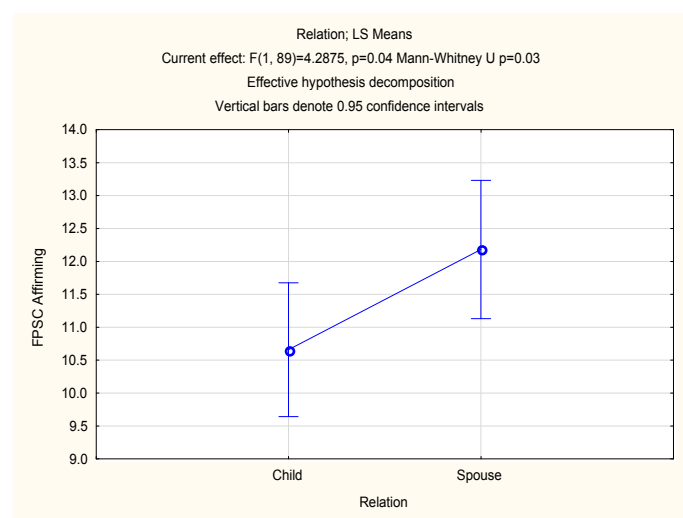


Figure 5.4 ANOVA: Results Obtained on the Affirming Communication Subscale of the FPSC.

Figure 5.4 shows that the spouse subgroup scored significantly higher than the child subgroup in the Affirming Communication Subscale of the FPSC, $F(1, 89) = 4.29$, $p = .04$, which measures the family's use of positive communication patterns that convey support and care and serve to calm a situation.

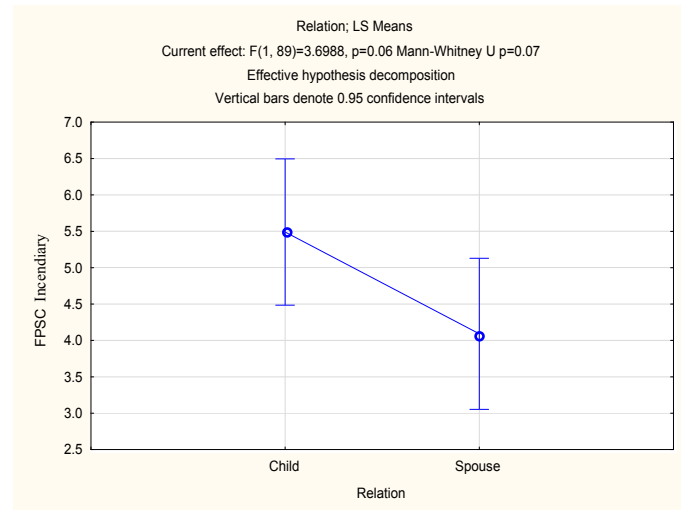


Figure 5.5 ANOVA: Results Obtained on the Incendiary Communication Subscale of the FPSC.

Figure 5.5 shows a tendency for the child subgroup to score higher on the Incendiary Communication Subscale of the FPSC than the spouse subgroup, $F(1, 89) = 3.70$, $p = .06$. This suggests that families in which adult children take on the role of caregiver more often experience negative communication patterns between family members, which often intensifies a stressful situation. These results were, however, not statistically significant ($p = .06$).

The results of the ANOVA on the total score of the FTRI are presented in Figure 5.6.

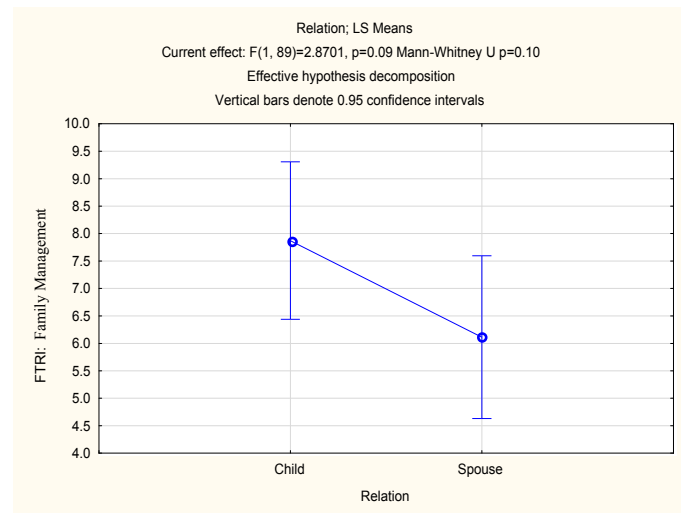


Figure 5.6 ANOVA: Results Obtained on the Family Management Routines Subscale of the FTRI.

Figure 5.6 shows that the child subgroup scored higher than the spouse subgroup on the Family Management Routines Subscale of the FTRI. Even though the difference is not statistically significant, $F(1, 89) = 2.87$, $p = .09$, there is a tendency that implies that families in which adult children take on the role of caregiver are more likely to attempt to create predictable routines that promote an atmosphere of family organisation and accountability, which they deem necessary to uphold family order in the home.

5.3.2 Pearson's product-moment correlations

Pearson's product-moment correlation coefficients were calculated to identify the independent variables that had a significant relationship with family adaptation (as measured by FACI8). The correlation coefficients for the spouse and child subgroups were calculated independently from each other to determine whether similar resilience strategies were associated with family adaptation in these subgroups. These correlation coefficients (r) and their corresponding significance values (p) are presented in Table 5.2.

Table 5.2

Pearson's Product-moment Correlations Found Between the Independent Variables and the Level of Family Adaptation as Measured by the FACI8 (N = 91)

Variable	Spouse (n = 44)		Child (n = 47)	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Family hardiness (FHI: Total)	.42	< .01**	.71	< .01**
Family's sense of internal strength, dependability and ability to work together (FHI: Commitment)	.30	.05*	.59	< .01**
Family's efforts to be innovative, active and to experience new things and to learn (FHI: Challenge)	.32	.04*	.56	< .01**
Family's sense of being in control of family life (FHI: Control)	.33	.03*	.63	< .01**
Overall problem-solving communication patterns (FPSC: Total)	.53	< .01**	.73	< .01**
Family's affirming communication patterns (FPSC: Affirming)	.58	< .01**	.72	< .01**
Family's incendiary communication patterns (FPSC: Incendiary)	-.40	< .01**	-.67	< .01**
Relative and friend support (RFS: Total)	.02	.90	.25	.09
Family's routines and activities (FTRI: Family Total)	.24	.12	.13	.37
Importance attributed to family time and routines (FTRI: Importance)	.14	.38	.13	.38

Table 5.2 (continued)

Variable	Spouse (n = 44)		Child (n = 47)	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Family's emphasis on creating predictable routines to promote children's sense of independence and order (FTRI: Child Routines)	.13	.39	.11	.46
Family's emphasis on creating predictable routines to encourage communication between spouses (FTRI: Couple Togetherness)	.23	.14	.17	.26
Family's attempts to create predictable routines to encourage togetherness through mealtimes (FTRI: Meals Together)	.06	.68	.07	.62
Family's emphasis on creating predictable communications between parents and children (FTRI: Parent-Child Togetherness)	.19	.22	.15	.31
Family's emphasis on family togetherness including special events, quiet time and family time (FTRI: Family Togetherness)	.35	.02*	.49	< .01**
Family's attempts to create predictable routines to encourage a meaningful connection with relatives (FTRI: Relative's Connection)	.30	.05*	.02	.91
Family's emphasis on establishing predictable routines to encourage children's responsibilities in the home (FTRI: Family Chores)	.14	.37	-.04	.79
Community support and the utilisation of community resources (SSI: Total)	.33	.03*	.35	.02*

Table 5.2 (continued)

Variable	Spouse (n = 44)		Child (n = 47)	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>P</i>
Family's attempts to create predictable routines to promote an atmosphere of family organisation and accountability necessary to uphold family order in the home (FTRI: Family Management)	.18	.24	.00	.98
Family's ability to actively engage in acquiring family, friend and neighbours support (F-COPES: Social Support)	.18	.24	-.03	.83
Total problem-solving and behavioural strategies families use (F-COPES: Total)	.26	.08	.16	.28
Family's capability to redefine events to make them more manageable (F-COPES: Reframing)	.29	.06	.07	.64
Family's ability to acquire spiritual support (F-COPES: Spiritual Support)	.12	.44	-.04	.81
Family's ability to seek out community resources and accept help (F-COPES: Mobilising Community Resources)	.06	.71	-.01	.94
Family's ability to accept problematic issues minimising reactivity (F-COPES: Passive Appraisal)	-.08	.59	.49	< .01**

* $p \leq .05$ ** $p \leq .01$

In the spouse subgroup, the independent variable with the strongest significant correlation with family adaptation (FACI8: Total) was affirming communication patterns (FPSC: Affirming communication), $r = .58$, $p < .01$. In contrast, incendiary communication patterns (FPSC: Incendiary communication) had a significant negative correlation with family adaptation (FACI8: Total), $r = -.40$, $p < .01$. The total FACI8 scores and the total FPSC scores had a correlation of $r = .56$ ($p < .01$) in the spouse subgroup. Similar results were obtained in the child subgroup. In the child subgroup, the independent variable with the strongest significant correlation with family adaptation (FACI8: Total) was family problem-solving communication patterns (FPSC: Total), $r = .73$, $p < .01$. In addition, family adaptation in this group had a strong positive correlation with affirming communication patterns (FPSC: Affirming communication), $r = .72$, $p < .01$, and a strong negative correlation with incendiary communication patterns (FPSC: Incendiary communication), $r = -.67$, $p < .01$. The results thus reveal that family adaptation in families caring for a family member diagnosed with dementia tends to be better in families who use more positive communication patterns and less negative communication patterns.

Family hardiness was also found to have a significant correlation with family adaptation. Family hardiness (FHI: Total) was significantly positively related to family adaptation (FACI8: Total) in the spouse subgroup, $r = .42$; $p < .01$, and in the child subgroup, $r = .71$; $p < .01$. The scores obtained with the FHI subscales – viz. the commitment subscale, the challenge subscale and the control subscale – were also positively correlated with FACI8 scores in both subgroups. The FHI: Commitment score and the total FACI8 score had a correlation of $r = .30$ ($p = .05$) in the child subgroup and a correlation of $r = .59$ ($p < .01$) in the spouse subgroup; the FHI: Challenge score and the total FACI8 score had a correlation of $r = .32$ ($p = .04$) in the child subgroup and a correlation of $r = .56$ ($p < .01$) in the spouse subgroup; and the FHI: Control score and the total FACI8 score had a correlation of $r = .33$ ($p = .03$) in the child subgroup and a correlation of $r = .63$ ($p < .01$) in the spouse subgroup. This implies that family adaptation had a positive relationship with the family members' ability to work together and depend on each other in times of hardship (FHI: Commitment); the ability of a family to reframe crises positively, learn new things and actively seek out new experiences (FHI: Challenge); and the family's perception of control regarding their own life (FHI: Control).

Routines that encouraged family members to spend time with each other (FTRI: Family Time Together) had a significant relationship with family adaptation in the spouse subgroup ($r = .35, p = .02$) and the child subgroup ($r = .49, p < .01$). In the spouse subgroup, a significant relationship was also found between routines that encourage a meaningful connection with relatives (FTRI: Relatives Connection) and family adaptation (FACI8: Total) ($r = .30, p = .05$). However, this relationship was not found in the child subgroup. No other family routines correlated significantly with family adaptation.

The results further revealed that social support had a positive relationship with family adaptation. The total score of the SSI had a significant positive correlation with the total FACI8 scores in both the spouse subgroup ($r = .33, p = .03$) and the child subgroup ($r = .35, p = .02$). This implies that family adaptation is better in families who are better integrated into their community, who more often find support in their community, and who regularly make use of community resources when caring for a family member with dementia. However, these results were not echoed in the results regarding support from relatives and friends. No correlation was found between family adaptation (FACI8: Total) and relative and friend support. Nevertheless, a tendency was noticed in the child subgroup that suggests a possible relationship between these variables, $r = .25, p = .09$.

With regard to coping strategies, a significant positive correlation was found between family adaptation and passive appraisal in families in which adult children were caring for their parent diagnosed with dementia, $r = .49, p < .01$. This implies that these families tend to experience better family adaptation if they accept their situation and minimise their reactivity towards it. This trend was not found in the spouse subgroup, however. No other coping strategies were related to family adaptation in the child subgroup. The spouse subgroup delivered no significant correlations between any of the coping strategies and family adaptation, but there was a tendency that suggested a possible relationship between the reframing of a situation to make it more manageable and family adaptation, $r = .29, p = .06$. The spouse subgroup also showed a tendency for a possible relationship between the total scores of the F-COPES and the total scores of the FACI8, $r = .26, p = .08$. Even though the results were not statistically significant, the tendency suggests a possible

positive relationship between family adaptation in families where spouses are caring for their partner diagnosed with dementia and their utilisation of positive problem-solving and behavioural strategies when faced with hardship.

5.3.3 Multiple regression analyses

A best-subset multiple regression analysis was conducted to identify the combination of independent variables that best predict the level of adaptation in families caring for a dementia patient. The findings of each caregiver subgroup were analysed independently. The results for the spouse subgroup are presented in Table 5.3 and the results for the child subgroup are presented in Table 5.4.

Table 5.3

Multiple Regression Analysis: The Best Combination of Predictor Variables for Family

Adaptation in the Spouse Subgroup (n = 44)

Variable	B	t(41)	P
Family hardiness (FHI: Total)	.08	1.05	.30
Overall problem-solving communication patterns (FPSC: Total)	.32	3.02	<.00**
Relative and friend support (RFS: Total)	-.09	-0.89	.38
Family's routines and activities (FTRI: Family Total)	.05	2.30	.03*
Community support and the utilisation of community resources (SSI: Total)	.11	1.55	.13

* $p \leq .05$

** $p \leq .01$

The results of the best-subset regression analysis, as illustrated in Table 5.2, shows a combination of five independent variables that best predicted family adaptation in families in which spouses care for their partner diagnosed with dementia, namely (a) family hardiness (FHI: Total); (b) the family's overall problem-solving communication

patterns (FPSC: Total); (c) friend and relative support (RFS: Total); (d) the type of activities and routines families engage in (FTRI: Family Total); and (e) community support and the utilisation of community resources (SSI: Total). The family's overall problem-solving communication patterns (FPSC: Total) was the statistically most significant predictor of the level of family adaptation in this subgroup, $B = .32$, $t(41) = 3.02$, $p < .01$. The type of activities and routines families engage in (FTRI: Family Total) were the only other variable identified that significantly contributed to the variation in family adaptation, $B = .05$, $t(41) = 2.30$, $p = .03$. The other variables identified in the regression analysis were not significant contributors to the variation in family adaptation. The best subset obtained in the regression analysis of the spouse subgroup had a multiple R value of .65, $F(5,38) = 5.65$, $p < .01$. The multiple R value indicates a significant positive correlation between the true FACI8 scores and the estimated FACI8 scores as predicted by the independent variables listed in Table 5.3. Furthermore, a multiple R^2 value of .43 was obtained, which indicates that the independent variables listed in Table 5.3 accounted for 43% of the variation in the FACI8 scores obtained in the spouse subgroup of the current study, $F(5, 38) = 5.65$, $p < .01$.

Table 5.4 presents the combination of independent variables that best predicted family adaptation in families in which adult children cared for their parent diagnosed with dementia, as identified by the multiple regression analysis.

Table 5.4

Multiple Regression Analysis: The Best Combination of Predictor Variables for Family

Adaptation in the Child Subgroup (n = 47)

Variable	B	t(41)	P
Overall problem-solving communication patterns (FPSC: Total)	.49	4.82	< .00**
Community support and the utilisation of community resources (SSI: Total)	.07	0.69	.49
Family's capability to redefine events to make them more manageable (F-COPES: Reframing)	.11	0.76	.45
Family's ability to seek out community resources and accept help (F-COPES: Mobilising Community Resources)	.14	-0.70	.49
Family's ability to accept problematic issues minimising reactivity (F-COPES: Passive Appraisal)	.19	1.05	.30

* $p \leq .05$

** $p \leq .01$

The p-values listed in Table 5.4 show that the B values of the total scores of the FPSC (Total score) differ significantly from zero, $B = .49$, $t(41) = 4.82$, $p < .00$. This illustrates the significant contribution of the family's overall problem-solving communication patterns to predicting family adaptation in families in which adult children care for their parent diagnosed with dementia. The B-value of the other variables identified does not differ significantly from 0, which implies that these variables were not statistically significant predictors of family adaptation in this subgroup. A multiple R value of .75 was obtained in the best subset of the child subgroup's regression analysis, which indicates that a significant positive correlation exists between the true FACI8 scores and the estimated FACI8 scores as predicted

by the independent variables listed in Table 5.4. The multiple R^2 value of .56 indicates that the independent variables listed in Table 5.4 account for 56% of the variation in the FACI8 scores obtained in the child subgroup of the current study, $F(5, 38) = 10.48, p < .01$.

A limitation of only considering the results of the best subset in the regression analysis is that the R^2 of the best subset might only differ marginally from other subsets. It could thus be argued that the variables identified as best predicting the level of adaptation might be included due to chance. To control for this limitation, the variables identified by the 20 best subsets of the regression analysis were compared with each other. These results are presented in Figure 5.7a and 5.7b.

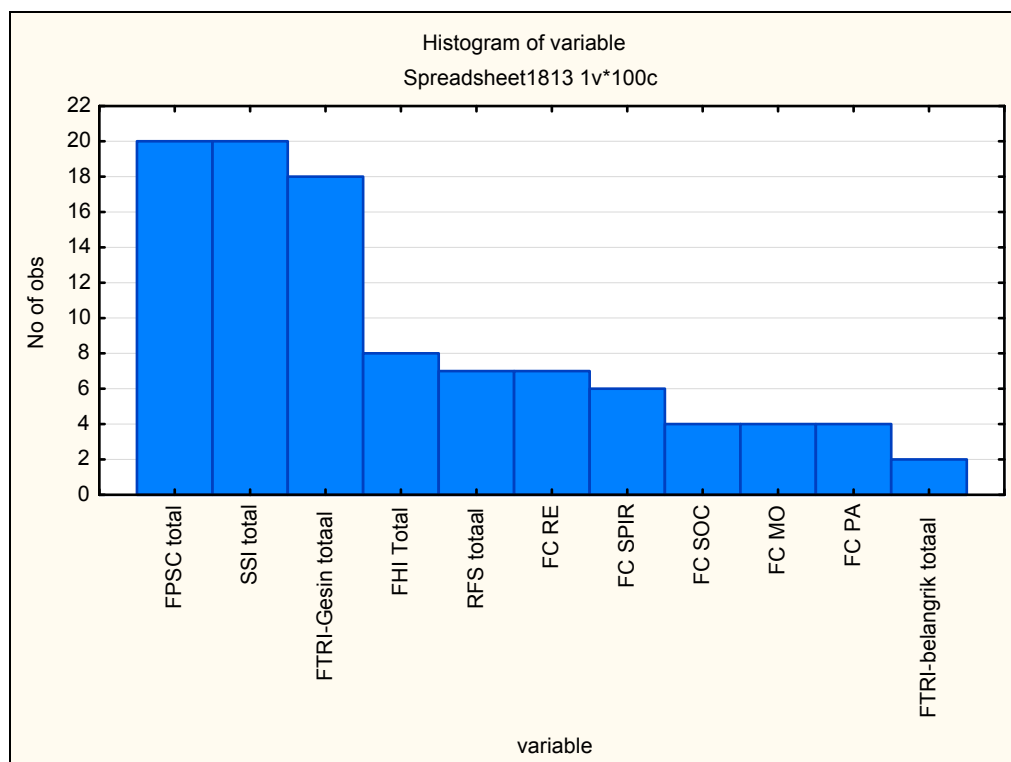


Figure 5.7a Histogram comparing the results of the 20 best subsets of the regression analysis (spouse subgroup)

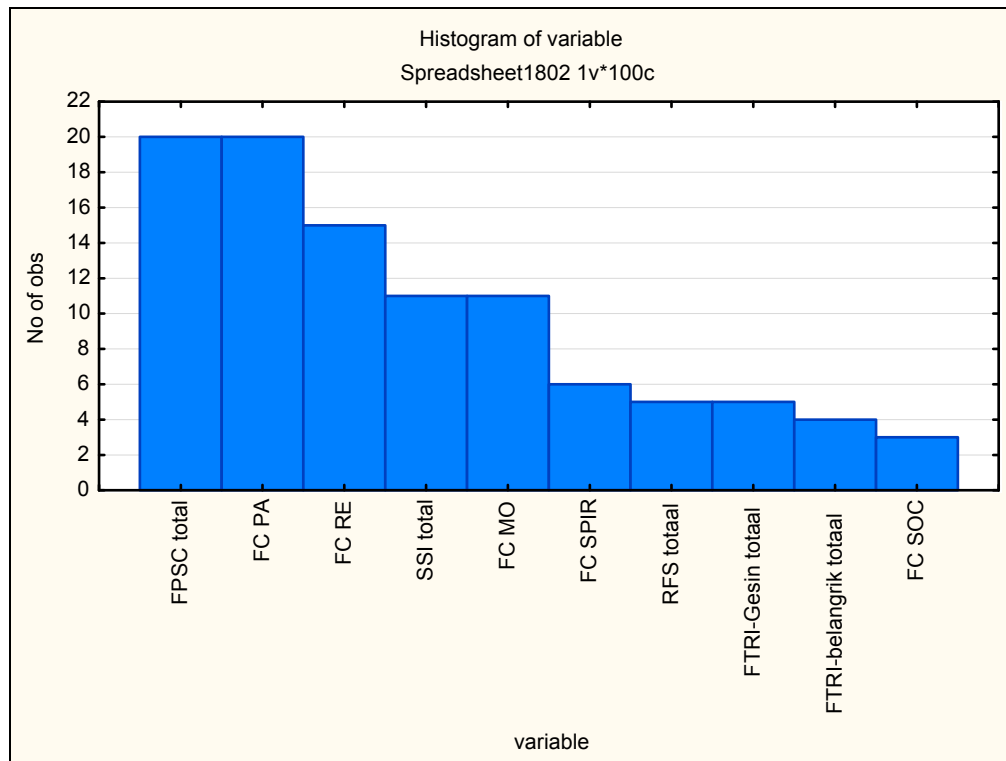


Figure 5.7b Histogram comparing the results of the 20 best subsets of the regression analysis (child subgroup)

Figure 5.7a and Figure 5.7b illustrate the number of times every independent variable was identified as a predictor of family adaptation in the 20 best subsets of the regression analysis. The results of the spouse subgroup are presented in Figure 5.7a. In this group, the FPSC: Total score was present in all the subsets compared, and the FTRI: Family Total score was in 18 of the 20 best subsets. The contribution of these variables to the variance in family adaptation was statistically significant in the best subset as well. These results indicate the significant contribution of problem-solving communication patterns and the types of activities and routines that families engage in to predicting family adaptation. The SSI: Total scores were also identified in all the best subsets as a predictor of family adaptation. Community support and the utilisation of community resources could thus be included as a predictor of family adaptation in the spouse subgroup, even though the contribution of this variable was not statistically significant. The FHI: Total score and the RFS: Total score were also included in the best subset as predictors of family adaptation. However, these variables were only present in eight (40%) and seven (35%) of the 20 best subsets respectively and neither made a statistically significant contribution to the variations

in family adaptation. The inclusion of these variables in the best subset could possibly be due to chance.

Figure 5.7b shows the results of the child subgroup. In this group, the FPSC: Total score was present in all the subsets compared, thus validating the previous findings identifying the family's overall problem-solving communication patterns as a strong predictor of family adaptation. The F-COPES: Passive appraisal scores were also identified in the 20 best subsets of the regression analysis. This suggests that passive appraisal could still be deemed as an important variable in the prediction of variation in family adaptation, even though the contribution of this variable to family adaptation was not statistically significant. The F-COPES: Reframing scores were identified in 15 (75%) of the 20 best subsets as a predictor of family adaptation. This implies that reframing a situation as a coping strategy contributes to the variance in family adaptation in the child subgroup, despite the fact that the contribution of this variable was not statistically significant. Even though the SSI: Total score and the F-COPES: Mobilising Community Resources score were included in the best subset as predictors of family adaptation, these variables were only present in nine (45%) of the 20 best subsets. Furthermore, the contribution of these variables to variations in family adaptation was not statistically significant. It is thus possible that these variables were only included in the best subset due to chance.

5.4 Qualitative Data

The aim of the qualitative section of the current study was to obtain a more in-depth understanding of resilience factors that helped the participating families to adapt and continue with life. Research shows that the viewpoints of participants are more likely to be expressed in relatively openly designed interviews than in structured, standardised questionnaires. A semi-structured interview allows participants to describe their beliefs in their own words and in their own time (Holloway, 1997). The participants thus were asked to elaborate on both family characteristics and external resources that helped them to adapt to caring for a family member with dementia. Due to time constraints, qualitative interviews with family representatives were conducted only until data saturation was achieved. As a result, only 40 participants were included in the qualitative data collection phase. The qualitative data was analysed via thematic content analysis, in which recurring themes and ideas were

identified through the examination and coding of the participants' responses. The data of the spouse and child subgroups was explored separately to determine whether it differed significantly in terms of resilience resources used. A summary of the themes that were identified in the qualitative analysis is depicted in Table 5.5.

Table 5.5

Resilience Resources as Identified by Spouses and Children (N = 40) in Qualitative Interview

Themes	Spouse (n = 19)		Child (n = 21)	
	Frequency	%	Frequency	%
INTERNAL FAMILY CHARACTERISTICS				
Actively maintaining a positive attitude (e.g. humour, personal time to escape from responsibilities, facing the illness one day at a time)	12	63%	18	86%
Acceptance	8	42%	9	43%
Spirituality and religion (e.g. prayer, Bible study)	14	74%	8	48%
Family connectedness	13	68%	13	62%
Good current relationship between family members	4	21%	12	57%
Good past relationship between family members	6	32%	7	33%
Spending time together (e.g. going away on holiday, shared recreational activities)	7	37%	6	29%

(Table continued)

Themes	Spouse (n = 19)		Child (n = 21)	
	Frequency	%	Frequency	%
Positive communication patterns	13	68%	16	76%
Open, clear communication	5	26%	11	52%
Patience, avoiding negative communication patterns	10	53%	11	52%
Flexibility	2	11%	3	14%
Consistency (e.g. constant family routines)	3	16%	3	14%
Characteristics of individual family members	7	37%	9	43%
EXTERNAL FAMILY RESOURCES				
Social support	19	100%	21	100%
Support from family members	17	89%	19	90%
Support from friends	6	32%	5	24%
Community support (e.g. neighbours, community groups)	8	42%	3	14%
Support from religious institution (e.g. church, prayer groups)	10	53%	1	5%
Support from others facing similar problems (e.g. support groups)	7	37%	7	33%
Hired help (e.g. hired nurses, day-care, respite care)	6	32%	13	62%
Support from doctors	6	32%	6	29%

(Table continued)

Themes	Spouse (n = 19)		Child (n = 21)	
	Frequency	%	Frequency	%
Social support (continued)				
Professional help (e.g. psychologists, social workers)	0	0%	2	10%
No community support	6	32%	9	43%
Social isolation	0	0%	7	33%
Financial support	-	-	-	-
Self-sufficient (do not get financial support)	7	37%	13	62%
Financial support from family members	5	26%	6	29%
MANAGING THE ILLNESS				
Managing symptoms (e.g. symptoms are not too severe, managing symptoms through medication or tried and tested strategies)	15	79%	16	76%
Information-seeking on dementia (e.g. books, internet, dementia groups)	7	37%	13	62%
Other stressors (e.g. stress at work, financial worries, intra-family conflict)	2	11%	6	29%

In the qualitative analyses, three general themes emerged: (1) internal family characteristics; (2) external family resources; and (3) managing the illness.

The qualitative results show that families made use of two external family resources to make them adapt to caring for a family member with dementia: social support and financial support. Social support was the only variable identified by all the participants in both family subgroups as contributing to family adaptation when caring for a family member diagnosed with dementia. This implies that all the

participants made use of some type of social support to help them adapt to their situation. The sources of support mentioned by the spouse and child subgroups were quite similar. The majority of the participants (89% in the spouse subgroup and 90% in the child subgroup) reported that physical and emotional support from family members helped their family to adapt to their situation. Both the spouse and child subgroups also reported the importance of support from friends (32% and 24% respectively). Support from others facing similar problems – which was mostly found at support groups – was identified as a resilience resource in 37% of the spouse subgroup and 33% of the child subgroup. Support from doctors was also deemed important in family adaptation by 32% of the spouse subgroup and 29% of the child subgroup. However, the family subgroups differed in terms of community support, support from religious institutions, and support from hired help. In the spouse subgroup, 42% of the participants used community support to help them adapt to their situation. On the contrary, only 14% of the child subgroup mentioned community support as an effective resilience resource. To a lesser extent, the differences between the two groups regarding community support were further strengthened by 33% of the spouse subgroup and 43% of the child subgroup who stated that they struggled to find community support. The spouse subgroup also deemed support from religious institutions as an important resilience resource (mentioned by 53% of this subgroup).

Religious institutions provided these families with emotional support. Church activities also acted as a social avenue through which the family members of the dementia patient could take a break from the troubles at home and just relax with other churchgoers. Prayer groups and church services also promoted spirituality, which acted as a buffer against crisis situations. One participant mentioned that the church provided care packages containing food to families in need. Nonetheless, the effect of support from religious institutions was mentioned by only 5% of the child subgroup. Conversely, the child subgroup more often made use of hired help. In the child subgroup, 62% of the participants mentioned the positive impact of hired help on family adaptation. Hired help included nurses or dementia caretakers hired by the family; elderly day-care facilities; or respite care, where families could drop off dementia patients for a few nights if needed. Families used these services as a way to take a break from their continuous caregiver responsibilities. These services were

only mentioned by 32% of the spouse subgroup. Professional help from therapists, psychologists or social workers was not very prominent in either family subgroup. In the child subgroup, 10% of the participants mentioned professional support as a resilience factor. None of the participants in the spouse subgroup made use of professional support. Finally, 33% of the participants in the child subgroup suffered from social isolation to some extent. These participants mentioned that friends were less likely to visit due to the condition of the dementia patient, and that their caregiving responsibilities made it very difficult to leave the house for socialisation. The impact of social isolation was not mentioned in the spouse subgroup at all.

The impact of financial support was not supported in these results. Most participants in the child subgroup (62%) felt that they were doing fine without any financial support from anyone. This was only stated by 37% of the spouse subgroup. The families who made use of financial support (26% in the spouse subgroup and 29% in the child subgroup) got financial backing from family members. None of the financial support was provided by government. One participant elaborated on this fact, explaining that the costs of treatment and medication – which are not covered by any medical aid – put immense financial strain on the family.

Several internal family characteristics were reported as helpful resources that promoted family adaptation. In the spouse subgroup, the internal family characteristic mentioned most often was spirituality (74%). These participants explained that their faith in God helped them to deal with their problems and adapt effectively to their situation. Spiritual activities, like prayer or meditation, helped family members to keep a positive attitude when things got rough. Furthermore, families who participated in church activities had access to emotional support, social support and, at times, even financial support that helped them adapt to their situation. The importance of spirituality was mentioned by only 48% of the child subgroup.

The most popular family characteristic reported in the child subgroup was optimism; 86% of the participants in this group actively sought out methods that helped them keep a positive attitude, despite their situation. Factors that helped family members maintain a positive attitude included positive thoughts; a sense of humour; taking

personal time to relax and escape from the continuous responsibilities of caregiving; taking on the illness one day at a time; and looking good. Optimism was popular in the spouse subgroup as well (mentioned by 68% of the participants).

Both the spouse subgroup and the child subgroup identified communication as an important factor in the resilience process (mentioned by 68% of the spouse subgroup and 76% of the child subgroup). More than half of the participants (53% of the spouse subgroup and 52% of the child subgroup) believed that patience was crucial when living with a dementia patient. They explained that it was easy to lose one's temper when dealing with this illness. These participants believed, however, that shouting and screaming were ineffective ways of dealing with the issues and that they were better able to cope with a situation once they had calmed themselves. Avoiding negative communication patterns were thus important in adapting to living with a loved one with dementia. In addition, clear, open communication patterns, in which the family members shared their troubles with each other, were identified as an important resilience factor by 52% of the child subgroup. However, only 27% of the spouse subgroup held this belief.

Factors that promoted family closeness were also identified as an important resilience characteristic in both the spouse and the child subgroups (mentioned by 68% and 62% of the participants respectively). A current relationship between family members that is characterised by love, care and affection was deemed vital in the adaptation process in these families; 57% of the child subgroup and 27% of the spouse subgroup mentioned their current relationship as a great motivator that helped them adapt to their situation. The past relationships between the household members and the patient also affected the level of family adaptation according to 32% of the participants in the spouse subgroup and 33% of the participants in the child subgroup. Other factors mentioned by a few of the participants included spending time with each other (mentioned by 26% of the spouse subgroup and 14% of the child subgroup) and including the patient in daily activities to help maintain their dignity (mentioned by 32% of the spouse subgroup and 19% of the child subgroup).

Acceptance of their current situation was also deemed an important resilience resource by several participants; 42% of the spouse subgroup and 43% of the child subgroup mentioned that acceptance played a key role in the adaptation process. They explained that family members were unable to adapt to the situation if they were not able to accept the diagnosis of the patient.

Individual characteristics of other family members identified by the participants as useful family resilience qualities included flexibility (mentioned by 11% of the spouse subgroup and 14% of the child subgroup) and stability through routines that simplified caregiving tasks (mentioned by 16% of the spouse subgroup and 14% of the child subgroup). Only one participant in the spouse subgroup and one participant in the child subgroup mentioned both flexibility and stability as resilience factors in families caring for a loved one diagnosed with dementia. The characteristics of individual family members were identified as resilience resources by 43% of the child subgroup and 37% of the spouse subgroup. The characteristic mentioned most often was the primary caregiver's past experience in caregiving. Other factors mentioned included friendliness, inner strength, and the use of avoidance coping strategies.

Managing the illness effectively was also a theme that was emphasised by several participants in both groups. The most important factor was to manage the symptoms of the illness effectively (as mentioned by 79% of the spouse subgroup and 76% of the child subgroup). In some cases, the participants viewed the symptoms of the patient as manageable, which made it easier to adapt to the situation. Others learned through trial and error what strategies work when dealing with problem behaviours, while others emphasised the importance of the right medication. Once the symptoms of the patient were more manageable, the families were better able to adapt. One of the strategies that helped participants manage the illness was information-seeking. Knowledge regarding dementia was identified as an effective resilience resource by the majority of participants in the child subgroup (62%). Only 37% of the spouse subgroup mentioned this resilience strategy. Sources of information used by the participants included the internet, pamphlets on dementia, books and articles on dementia, talks organised by organisations such as Dementia South Africa and Alzheimer's South Africa, television and radio programmes

focusing on this illness, dementia support groups, friends or family who have gone through the same experience, and the doctors who diagnosed the patient.

Other problems faced by families caring for a loved one diagnosed with dementia put more stress on the family members. This pile up of stressors made it harder for the family to deal with everything they were struggling with. The participants often mentioned troubles at work, financial worries, and intra-family conflict as stressors that made it more difficult to adapt to the situation.

In Chapter 6, the findings presented in this chapter will be compared with the theoretical framework of the current study and other literature regarding dementia, family resilience and family caregiving.

CHAPTER 6

DISCUSSION

6.1 Introduction

The primary aim of this study was to identify, explore and describe resilience factors that are present in families caring for a family member diagnosed with dementia. The study focused on families in which spouses and adult children were caring for a loved one diagnosed with dementia. The family resilience factors of these family subgroups were explored separately and were compared with each other to determine whether any significant differences existed between the subgroups regarding the prevalence of family resilience factors. McCubbin and McCubbin's (1996) Resiliency Model and Walsh's (2002, 2003) Family Resilience Framework provided the theoretical foundation of the current study. In this chapter, the results presented in Chapter 5 will be discussed with reference to the literature reviewed in Chapter 3. The results will also be linked to the theoretical framework of the current study, as discussed in Chapter 2. The chapter will commence with a short discussion of the severity of the stressor that triggered the crisis event and its impact on family adaptation. Furthermore, the results will be discussed in terms of the three family domains that promote family resilience during crisis situations, as identified by Walsh (2002, 2003), viz. (1) family belief systems, (2) organisational patterns, and (3) communication. The impact of individual characteristics on adaptation in families caring for a family member diagnosed with dementia will be discussed as well. This chapter will conclude with a summary of the findings and the limitations of the present study, and suggestions will be made for future research.

6.2 Stressor Event

Unanticipated, non-normative stressors, like caring for a loved one with dementia, regularly lead to significant risk due to the unexpected and traumatic nature of the event. When caring for a chronically ill patient, the objective severity of the patient's illness might disrupt family functioning, threaten the stability of family systems, and drain family resources (Lavee et al., 1987; Patterson, 2002a, 2002b). A negative

relationship between the severity of dementia symptoms and family adaptation therefore was expected in the current study.

The qualitative results of both family subgroups in the present study reveal that adaptation was easier if the dementia symptoms were less severe and more manageable. Some family representatives believed that the illness did not disrupt their daily lives, thus making it easy to adapt. Others managed the symptoms through medication or other tried and tested strategies. However, no quantitative measuring instrument was used to gather data on the participants' perceptions regarding the severity of the dementia patient's symptoms. The relationship between family adaptation and symptom severity could thus not be validated quantitatively. Furthermore, the results were based on the subjective judgements of family caregivers. The influence of the severity of the stressor on family adaptation would be presented better by results obtained through an objective questionnaire measuring this variable.

The literature review delivered several studies that supported the findings of the qualitative results regarding the severity of the stressor on family adaptation. Bester's (2009) study on resilience in families in which a parent has been living with depression showed a statistically significant, negative correlation between the depression levels of the patient and family adaptation. The negative impact of stressor severity has also been emphasised in studies on burden in dementia caregivers. Pattanayak et al. (2010) found that burden in family caregivers of dementia patients was significantly predicted by the duration of the illness and the severity of the patient's cognitive impairment. In the qualitative results of Haley et al.'s (1987) study, however, the severity of objective caregiving stressors was not correlated statistically with caregiver outcomes. In the stepwise regression analysis, these stressors accounted for very little of the variance in life satisfaction, caregiver depression and health. Carnes and Quinn (2005) found that the emotional and behavioural changes in the patient after a brain injury had a significant positive correlation with negative factors in individual family members (like psychological distress), but that this was not correlated significantly with family functioning. According to Carnes and Quinn (2005), family members tend to band together when

dealing with hardship, thus buffering the family unit against negative outcomes caused by the stressor event.

In the current study, 11% of the spouse subgroup and 29% of the child subgroup mentioned that the negative effect of additional stressors (like troubles at work, financial worries and intra-family conflict) made it harder for the family to adapt to their situation (see Table 5.5). According to McCubbin and McCubbin (1996), families are generally influenced by their social and cultural environment and are continuously subject to multiple stressors in these environments. If a new stressor surfaces, prior strains are often exacerbated, which could hinder the family's ability to adapt (Lavee et al., 1987; McCubbin & McCubbin, 1996).

6.3 Family Belief Systems

6.3.1 Making meaning of adversity

In the current study, acceptance was quite a prominent theme in the qualitative findings (see Table 5.5); 42% of the participants in the spouse subgroup and 43% in the child subgroup mentioned that, to be able to adapt, they first had to accept the situation as it was and make the most of it. The acceptance of a stressor event is also mentioned in the theoretical framework of the current study. Walsh's (2002, 2003) Resilience Framework explains that the family's ability to accept a crisis event (like caring for a family member with dementia) has a significant influence on their competence in selecting an adequate coping response.

Both family subgroups mentioned the importance of knowledge regarding dementia, its symptoms and methods for managing the symptoms. The internet and dementia societies, like Dementia South Africa and Alzheimer's South Africa, were the most used sources of information. The participants believed that family adaptation was easier if everybody in the family understood that certain behaviours by the patient (like aggression) were part of the illness. They explained that, by educating themselves and each other on the nature and symptomatology of the illness, they were better able to understand the behaviour of the patient, thus making it easier to accept and adapt to the situation. Information on the illness prepared family members for what to expect in the future as well. However, children caring for their

parent diagnosed with dementia identified information-seeking as a resilience resource more often than spouses caring for their partner diagnosed with dementia in the current study.

McCubbin and McCubbin's (1996) Resiliency Model and Walsh's (2002, 2003) Resilience Framework both identified a family's appraisal of a stressor event as crucial in the family's adjustment and adaptation processes. Families need to make sense of unexpected crises before they can effectively respond to the situation. Information-seeking is a key element in this meaning-making process and helps families to normalise and contextualise their situation. By rendering the crisis situation understandable and manageable, families are able to maintain a sense of control over their environment, which fosters confidence that their circumstances will ultimately work out in a favourable way. In Greeff and Thiel's (2012) study of resilience in families in which a husband had been diagnosed with prostate cancer, information-seeking was identified as a resilience resource that helped families to accept the diagnosis; made them feel more involved in the decision-making process; and lowered the anxiety levels of family members, thus promoting a more positive outlook regarding the family's future. Jonker and Greeff (2009), who studied resilience factors in families caring for a family member with a mental illness, also found that a better understanding of the illness facilitated family adaptation. The importance of information-seeking was also stressed in studies that focused on the burden of family caregivers of dementia patients. These studies found that knowledge helped the caregivers to understand the impact of the illness on the dementia patient. Well-informed family caregivers were thus more likely to respond to the difficulties of the illness in a positive way that relieved stress and ultimately reduced depression (Quinn et al., 2008; Yamashita & Amagai, 2008; Zarit, 2008). Moreover, self-reported health behaviours were higher in caregivers who actively sought information (Haley et al., 1987). Dementia caregivers obtained information via self-help books, structured educational programmes, support groups and informational sessions run by the local government or by non-profit organisations like the Alzheimer's Association (Yamashita & Amagai, 2008; Zarit, 2008).

In the present study, the subjective appraisal of families regarding the stressors associated with dementia care was not assessed directly using a quantitative

measurement. Nonetheless, the results obtained with the Passive appraisal and the Reframing subscales of the F-COPES suggested a positive relationship between family adaptation and the meaning-making process. Families in which adult children were caring for their parents diagnosed with dementia showed a significant positive correlation between family adaptation and passive appraisal (see Table 5.2), implying that family adaptation tended to be better in families who accepted their situation and who minimised their reactivity towards it. These findings were supported by the child subgroup's best-subset multiple regression analysis (see Table 5.4), in which passive appraisal as a coping strategy was identified as one of the independent variables that best predicted family adaptation. Even though this finding was not statistically significant, passive appraisal was identified in the 20 best subsets of the regression analysis (see Figure 5.7b), thus validating the importance of passive appraisal in the prediction of variation in family adaptation. Conversely, neither the Pearson's product-moment correlation coefficients, nor the best-subset regression analysis of the spouse subgroup, showed a significant relationship between passive appraisal and family adaptation. The spouse subgroup showed a tendency that suggested a possible relationship between family adaptation and the reframing of a situation to make it more manageable. However, these results were not statistically significant. The multiple regression analysis of the child subgroup also identified the use of reframing as a coping strategy as a predictor of the variance in family adaptation in the current study. However, this finding was also not statistically significant. Even so, the contribution of a family's ability to reframe a crisis situation to the variance in family adaptation was confirmed in 15 (75%) of the 20 best regression subsets (see Figure 5.7b), which implied that reframing a situation to make it more manageable contributed to the variance in family adaptation.

Other family resilience studies have produced mixed findings regarding the influence of passive appraisal on family adaptation. The results of the current study are supported by those of Bester (2009) and Greeff et al. (2006), who both found a statistically significant positive correlation between family adaptation and passive appraisal. These findings were supported in the regression analysis of the child data in Bester's (2009) study, which revealed that passive appraisal contributed significantly to the prediction of family adaptation. In contrast, Jonker and Greeff

(2009) found a significant negative correlation between family adaptation and passive appraisal. Once again, this premise was strengthened by the results of the multiple regression analysis, which also showed a negative relationship between passive appraisal and family adaptation. The results thus imply that families adapt better if they deal with crises proactively, rather than passively accepting the situation. Carnes and Quinn (2005) found no significant correlations between family functioning and passive appraisal. They attributed these results to the difficulties connected to the operationalisation and assessment of the meaning-making process, thus implying a need for better instruments to measure this factor. A statistically significant positive correlation between family adaptation and reframing a crisis situation as a coping strategy has been found in several studies on family resilience (Bester, 2009; Greeff et al., 2006; Greeff & Thiel, 2012; Greeff & Wentworth, 2009). These findings have theoretical support as well. Both family Resiliency Models used in the current study explain that the resilience process is facilitated by a family's ability to reframe a problem as a challenge that is comprehensible, manageable and meaningful to tackle. This resilience resource helps families to maintain a sense of control over their internal and external environments, thus promoting positivity and hope within the family unit (Hawley, 2000; Lavee 1987; McCubbin & McCubbin, 1996; Walsh, 2003).

6.3.2 Positive outlook

According to Walsh's (2003) Family Resilience Framework, an optimistic view of life is a key family resilience resource that fosters hope for the future and provides families with the strength to rise above adverse circumstances. Positivity helps families to reframe crises in such a way that they seem manageable; reinforces confidence, pride and a "can do" attitude; and normalises and contextualises the family's distress regarding the crisis situation, thus ultimately reducing feelings of blame, shame and guilt (Black & Lobo, 2008; Walsh, 2003). In the current study, it was thus expected that an optimistic view of life and the utilisation of resources that maintain positivity within the family unit would be associated with better family adaptation.

As expected, the qualitative data showed that most families actively sought out ways to maintain a positive attitude (see Table 5.5). Both the spouse subgroup and the

child subgroup warned against the negative effects of continuous exposure to the stressors associated with dementia care. They emphasised the need to take a break from caregiving now and then to focus on their own well-being and separate themselves from the worries of their caregiving role. Hobbies – like reading, listening to music, taking a drive, gardening, or going for a walk – helped family members to clear their heads when times got tough. The participants also emphasised the need to promote positive thoughts, which often meant avoiding thoughts regarding the future and focusing on the blessings that shine through during the caregiving experience. Some participants identified a sense of humour as a vital family resilience resource.

The literature on family resilience supported the results of the current study regarding the effect of optimism on family adaptation. Greeff and De Villiers (2008), who focussed specifically on the effect of hope and optimism on family adaptation after the death of a parent, confirmed that higher levels of optimism and hope were significantly related to better family adaptation. Factors that promote positivism and optimism include the positive attitude of an individual family member; family closeness; mutual support; focusing on the positive; an appreciation for what the family has; improving the self and striving towards personal success; an inclination to move on; religious beliefs; and a sense of humour (Greeff & De Villiers, 2008). Greeff and Wentworth (2009) also found that a positive outlook was one of the individual characteristics that best facilitated family adaptation. Optimism has also been identified as a key factor in the buffering of burden in the family caregivers of dementia patients. Gottlieb and Rooney (2004) found that optimism had a significant impact on coping behaviours, coping effectiveness, and outcome expectancies in family caregivers of dementia patients. Quinn et al. (2008) also found a positive relationship between optimism and coping. These findings are supported by Walsh (2003), who found that hopeful, optimistic families were still aware of reality, such as a poor prognosis, but consciously chose to make the most of the options available to them. Nevertheless, Walsh (2003) believes that families adapt better if they take initiative, seize opportunities, and search for solutions instead of just passively accepting the situation without responding to it. Haley et al. (1996), who studied racial differences in appraisal, coping and social support in family caregivers of patients with Alzheimer's disease, also found that avoiding the problem could have

negative effects on the caregivers of dementia patients. They found that avoidance coping strategies were significantly related to lower levels of life satisfaction and higher levels of depression. Conversely, high levels of approach coping were related to higher levels of life satisfaction and lower levels of depression.

The quantitative results obtained in the present study mirrored the study's qualitative findings regarding the importance of optimism in the adaptation of families caring for a loved one with dementia. None of the quantitative measures assessed the optimism of families directly. However, family hardiness (as measured by the total score of the FHI) – which facilitates an optimistic family outlook (Greeff et al., 2006) – had a significant positive correlation with family adaptation. The FHI subscales – viz. the commitment subscale, the challenge subscale and the control subscale – were all positively correlated with family adaptation in both subgroups (see Table 5.2). Family adaptation thus tended to be better in families who (a) tried to maintain a positive attitude during adverse conditions by viewing life changes and obstacles as a normal part of life that has the potential to bring about opportunities for growth (FHI: Challenge subscale); (b) believed that they had a significant influence on the eventual outcome of life events and actively pursued the best outcome possible (FHI: Control subscale); and (c) relied on each other and worked together as a family unit to rise above adversity (FHI: Commitment subscale) (McCubbin et al., 1996b). The results of the best-subset multiple regression analysis identified family hardiness as one of the five independent variables that best predicted family adaptation in families where spouses care for their partner diagnosed with dementia (see Table 5.3). However, the contribution of family hardiness to the variation in family adaptation was not statistically significant. Furthermore, the results revealed that family hardiness was only present in eight (40%) of the 20 best regression subsets that identified the best combination of variables that predicted family adaptation (see Figure 5.7a), thus implying that the inclusion of this variable in the best regression subset could possibly be due to chance.

The relationship found between family hardiness and family adaptation is echoed in the works of McCubbin and McCubbin (1996), who identified family hardiness as a vital resource in the resilience process. The positive relationship between family hardiness and family adaptation was also confirmed in the studies by Bester (2009),

Greeff et al. (2006), Greeff and Thiel (2012), Greeff and Wentworth (2009) and Preece and Sandberg (2005). However, in Greeff and Thiel's (2012) study, the correlation found between family resilience and overall family hardiness was not supported by the results of the subscales of the Family Hardiness Index. A statistically significant correlation was only found in the wives subgroup between family adaptation and the commitment and control components of family hardiness. In the husbands subgroup, none of the three components of family hardiness obtained a statistically significant correlation with family adaptation. Greeff and Thiel (2012) explain that this inconsistency might have been caused by the relatively low internal reliability of the subscales in their study. Family hardiness was not identified as a significant defence against caregiver burden by any of the dementia studies. However, self-efficacy (a feature that describes how individuals evaluate their own ability to master a specific task successfully) is an inherent characteristic of family hardiness. Gilliam and Steffen (2006) found a significant negative correlation between self-efficacy and depressive symptoms. Au et al. (2009) found that self-efficacy in dementia caregivers had a negative correlation with depressive symptoms and a positive relationship with well-being.

6.3.3 Transcendence and spirituality

Walsh's (2002, 2003) Family Resilience Framework identified spirituality as a valuable resource that facilitates family adaptation. Walsh (2003) explains that spiritual beliefs and cultural/religious traditions empower families by providing meaning and purpose beyond themselves and their current problems. Spiritual practices, like prayer and meditation, strengthen families and provide them with guidance and comfort. In addition, religious or congregational affiliations connect families to a larger community that provides support and comfort during adverse situations (Black & Lobo, 2008; Walsh, 2003). Greeff and Joubert (2007) revealed that faith and spirituality play a significant role in family adaptation when dealing with loss and suffering. Families find comfort in their belief that God is ultimately in control and that He would not allow hardship without a reason. Due to the poor prognosis of the illness and the sense of loss experienced by family members when caring for a loved one with dementia, it was expected that spirituality would play a significant role in the family adaptation process in the current study.

The qualitative results of the current study revealed that families from both subgroups made use of spiritual support when adapting to caring for a loved one diagnosed with dementia. Second to social support, spirituality was one of the resilience resources mentioned the most in the spouse subgroup. These families believed that God gave them the strength to continue during difficult times and would not permit their situation if not for a purpose. Family members who formed part of a religious congregation often used church activities as an escape from their caregiving responsibilities and often received emotional support from fellow churchgoers. However, spirituality was mentioned more often as a resilience resource in the spouse subgroup than in the child subgroup. The qualitative responses in both Greeff and Thiel (2012) and Jonker and Greeff's (2009) studies reflect the positive impact of spirituality on family adaptation. Haley et al. (1996) also found that the majority of both white and black family caregivers made use of religion as a coping mechanism through prayer, church attendance and church group meetings. In contrast, Yamashita and Amagai (2008), who explored the experiences of family caregivers in Japan caring for a relative with dementia, found that the participants failed to mention faith in God's help as a coping strategy. Yamashita and Amagai (2008) explained that this finding could be due to the ambiguous nature of religiosity as a concept. They also argued that the lack of religiosity as a coping mechanism might be due to caregivers taking on a worldview that is existential in nature. Yamashita and Amagai's (2008) results are in contrast to the findings of the current study. However, these differences could be attributed to the cultural differences between the Japanese and South African populations.

The F-COPES: Spiritual support subscale was used to measure the family's tendency to use spiritual and religious support as a coping strategy. In contrast to the qualitative data, no significant correlation was found between this variable and family adaptation (see Table 5.2). The regression analysis on the data of both the child and spouse subgroups did not identify spiritual support as a predictor of family adaptation. These contrasting results could possibly be attributed to the nature of the items in the measuring instrument (F-COPES: Spiritual support subscale), where items measure the extent to which families elicit spiritual support from the community. Most of the items focus on the families' involvement in a religious or congregational affiliation and neglect the spiritual support provided through personal

or familial rituals that are centred on spirituality (e.g. prayer, meditation, family Bible study). In the qualitative interviews the participants mentioned that they found it difficult to attend spiritual gatherings or congregational activities due to the demanding nature of dementia. However, they still practised their spirituality at home and deemed it essential in the adaptation process. The F-COPES: Spiritual support subscale has been used in several studies that focus on family resilience in families caring for a chronically ill patient. Greeff et al. (2006), Greeff and Thiel (2012) and Jonker and Greeff (2009) also found no significant relationship between spirituality and family adaptation. As in the current study, the qualitative results of these studies contradicted the quantitative results. Jonker and Greeff (2009) explained that this inconsistency found in the answers of the participants might be due to the ambiguity of the spiritual support items in the F-COPES: Spiritual support subscale. However, in Bester's (2009) study on resilience qualities present in families with a parent living with depression, the child subgroup revealed a significant correlation between seeking spiritual support and family adaptation. Carnes and Quinn (2005) also found a significant correlation between family functioning and spiritual support.

6.4 Family Organisational Patterns

6.4.1 Flexibility

According to the Family Resilience Framework suggested by Walsh (2002, 2003), families tend to function best when a sense of balance is achieved between flexibility and structure. On the one hand, flexibility is described as a vital resilience resource that helps families to construct a new sense of normality that better accommodates the circumstances brought about by a crisis situation. On the other hand, stability and continuity maintain the integrity of the family unit as a system and provide families with feelings of cohesion, comfort and predictability, which compensate for the disruptive effects of change (Black & Lobo, 2008; Patterson, 2002b; Walsh, 2003). It was expected that the balance between flexibility and stability would play a significant role in the adaptation of families in which a family member was diagnosed with dementia.

Contrary to expectations, very little support for the balance between flexibility and stability was obtained in the current study. In the qualitative results, 16% of the

spouse subgroup and 14% of the child subgroup mentioned routines as an important resilience factor. Flexibility was mentioned by only 11% of the spouse subgroup and 14% of the child subgroup. Only one participant in each family subgroup mentioned both stability and flexibility as a resilience resource. The quantitative results did not provide much support for this variable either. The current study evaluated the type of activities and routines families engage in, using the Family Time and Routine Index (FTRI), but no significant correlation was found between this variable and family adaptation in either of the family subgroups. The only set of routines that was significantly correlated with family adaptation in both the spouse and the child subgroup was routines that encourage family members to spend time with each other (FTRI: Family time together) (see Table 5.2). In the spouse subgroup, a significant relationship was also found between routines that encourage a meaningful connection with relatives (FTRI: Relatives connection) and family adaptation, but this relationship was not found in the child subgroup. No other family routines correlated significantly with family adaptation. However, the results of the multiple regression analysis showed that the types of activities and routines that families engage in (FTRI: Family Total score) contributed significantly to the variation in family adaptation in families where spouses cared for their partner diagnosed with dementia. The FTRI: Family total score was present in 18 of the 20 best regression subsets (see Figure 5.7a). The lack of quantitative support regarding the importance of routines in families in which a family member is diagnosed with dementia could possibly be attributed to the nature of the items in the measuring instrument used to assess this variable. The participating families consisted mostly of adults living together without any children under the age of 18 in the household. The items in the FTRI mostly assume that a child was still living in the household, and most items regarding daily routines are focused on the children. The terminology used in the items also suggests the presence of children in the household, even when they are not part of the statement (e.g. "Fathers do regular household chores"). As a result, these items were mostly deemed inapplicable in the current study.

In contrast to the present study, both Bester (2009) and Greeff and Wentworth (2009) found a statistically significant positive correlation between family time and routines (as measured by the FTRI Family Total score) and family adaptation. The regression analysis of the spouses' data in Bester's (2009) study confirmed these

results; family time and routines was identified as a statistically significant predictor of family adaptation. In Bester's (2009) results, the data from both the spouses and the children showed a positive correlation between family adaptation and routines that promote couple togetherness, parent-child togetherness, and family time together. In addition, routines that encourage a meaningful connection with relatives, parent chores, and family management and organisation were significantly correlated with family adaptation in the spouse subgroup. These results were not reflected in the child subgroup. Greeff and Wentworth (2009) only found a statistically significant correlation between routines that promote child and adolescent responsibilities in the home and family resilience. These authors also found that flexibility plays a major role in family adaptation. Due to the disabling nature of heart-related trauma, family members often have to take over some of the patient's responsibilities. The family's ability to adapt to these role changes plays an important part in the family's recovery process. These results were also found in studies on burden in the caregivers of dementia patients. Zarit (2008) reported reduced depression levels in families who made use of structured routines. Difficult caregiving tasks can become mundane if the same tried and tested routines are used when dealing with these everyday problems. However, Zarit (2008) found that some strategies might become obsolete as the illness progresses. Caregivers need to be flexible enough to allow for new strategies when old routines are no longer effective. Quinn et al. (2008) found that routines often simplified the daily responsibilities of family caregivers and helped them to effectively deal with their situation. However, their study also showed that caregivers had to be flexible enough to adjust their coping strategies when dealing with new circumstances.

6.4.2 Connectedness

The theoretical framework in the current study identified cohesiveness, which is characterised by mutual support, commitment and collaboration, as a significant resilience resource. Families have to rely on each other during crises to overcome the difficulties of the situation (Black & Lobo, 2008; Patterson, 2002b; Walsh, 2003). The relationship between family adaptation and connectedness was highlighted in the qualitative and quantitative findings of the current study.

In the qualitative interviews, both family subgroups identified factors that promoted family connectedness as an important resilience characteristic (see Table 5.5). Firstly, more than half of the participants in the child subgroup identified the current relationship between family members as an important resilience resource. The family representatives explained that the love and displays of affection between family members motivated them to make the best of their situation and provided them with emotional support when they felt down. Furthermore, the love family members felt for the dementia patient also made caregiving less burdensome. Secondly, 32% of the participants in the spouse subgroup and 33% of the participants in the child subgroup mentioned that the past relationship between the household members and the patient affected the level of family adaptation. Family representatives who described the patient as a loving spouse/parent explained that caring for the dementia patient was simply the method in which the family expressed their gratitude for the support they had received in the past. The memory of the patient motivated them to overcome the difficulties of the illness and kept them positive.

A similar theme regarding family connectedness was reported in Jonker and Greeff's (2009) qualitative results. Family characteristics such as practical support, emotional support, mutual respect and love for one another were identified as key resilience resources. Likewise, Preece and Sandberg (2005) found that conflict in the family was related to higher levels of family distress, more severe FMS symptoms in the patient, and increased functional disability in the patient. The importance of a good current relationship between the caregiver and the dementia patient was stressed by Ablitt et al. (2009), who conducted a systematic review of studies investigating the relationships between dementia patients and family caregivers. They found a connection between lower current relationship quality and greater levels of depression, increased strain, and lower perceived self-efficacy in caregivers. Furthermore, current relationship quality influenced the dementia patient in terms of psychological well-being, problem-solving ability and functional ability. In accordance with the qualitative findings of the current study, Ablitt et al. (2009) and Yamashita and Amagai (2008) found a negative correlation between the relationship quality of the caregiver and patient prior to the onset of dementia and caregiver burden. Ablitt et al. (2009) added that better prior relationship quality was related to better problem-

solving and communication patterns, a better sense of reward and satisfaction, and a higher quality of life.

The qualitative results of the current study reveal that family adaptation was promoted through time spent together with family members (as mentioned by 37% of the spouse subgroup and 29% of the child subgroup). The participants explained that the emotional burden of living with a loved one with dementia was buffered when family members spent time together and supported each other. Spending time with the patient was also described as a positive experience during which they could enjoy their time left together. These families also included the patients in household chores, like cooking or gardening, which lessened the responsibilities of the caregiver and upheld the dignity of the patient, thus contributing to family resilience. These results were verified by the quantitative findings of the current study, which revealed a positive, statistically significant correlation between the family members' ability to work together and depend on each other in times of hardship (as measured by the FHI: Commitment subscale) and family adaptation in both the spouse and child subgroups (see Table 5.2). The quantitative findings of both the spouse and the child subgroups in the current study also showed a significant positive correlation between family adaptation and routines that encouraged family members to spend time with each other (as measured by the FTRI: Family Time Together). In addition, the spouse subgroup obtained a significant positive correlation between routines that encouraged a meaningful connection with relatives (FTRI: Relatives connection) and family adaptation (see Table 5.2). Bester (2009) reported a significant correlation between family adaptation and family routines that promote couple togetherness, parent-child togetherness, and family time together in both the spouse and child subgroups. The spouse subgroup also showed a significant relationship between family adaptation and family routines that promote connectedness with relatives. Greeff and Wentworth (2009) found a positive correlation between family adaptation and routines that promote parent-child togetherness. Black and Lobo (2008) also reported that shared recreation and leisure time promoted attachment, happiness, the development of a sense of humour, learning, and the enjoyment of shared experiences.

Ablitt et al. (2009) and Mitrani and Czaja (2000) found a positive relationship between high levels of cohesion prior to the diagnosis of the illness and increased distress in caregivers. Mitrani and Czaja (2000) explained that caregivers with higher levels of connectedness with the dementia patients often were unwilling to delegate caregiving tasks, thus making it harder to run the caregiving system effectively. Losada et al. (2010), who analysed the influence of cultural and cognitive variables on depression in caregivers, found that familism – which is characterised by high levels of family connectedness – was a multidimensional construct that had both positive and negative effects on caregiver distress. On the one hand, families with high family connectedness were more likely to use the family as a reliable source of support, which had an indirect positive effect on caregiver distress. On the other hand, these families often fostered rigid views regarding family caregiving, which would lead to dysfunctional thought patterns that induce psychological stress in the caregiver. In addition, intra-familial conflict erupted when the behaviours and attitudes of family members did not adhere to these rigid views.

According to the theoretical framework directing this study, families needed to balance their degree of connectedness and separateness to optimise family functioning. Even though these caregivers need emotional connectedness, they also need to function as separate individuals (Black & Lobo, 2008; Patterson, 2002b; Walsh, 2003). The balance between connectedness and individuality described in the literature was not apparent in the qualitative or the quantitative results of the current study.

6.4.3 Social support

Both the qualitative and quantitative results of the current study revealed that social support plays a crucial role in the adaptation process of families caring for a family member diagnosed with dementia. These findings enjoy theoretical support in terms of the Resiliency Model of McCubbin and McCubbin (1996) and the Resilience Framework proposed by Walsh (2002, 2003). Walsh (2002, 2003) believes that resilient families have the strength to admit when they need help and are more likely to utilise the available support structures when faced with adversity. In the Resiliency Model (McCubbin & McCubbin, 1996), a family's social support, which could be informal (e.g. extended family, friends) or formal (e.g. medical professionals,

schools, churches), is viewed as an important buffer of stress that promotes family well-being. In the current study, three types of social support were identified as useful resilience resources: (1) informal support from extended family and friends, (2) community support, and (3) professional support.

In the present study, participants in both family subgroups mentioned informal support from family and friends as an effective resilience resource. Physical and emotional support from family members was deemed a crucial element in the adaptation process when caring for a family member diagnosed with dementia. Both the spouse and child subgroups also reported the importance of support from friends (see Table 5.5). The importance of familial support could offer a possible explanation for the correlation found between the number of adults in the household and family resilience. In the child subgroup, the number of adults in the household had a statistically significant, positive relationship with family adaptation (see Table 5.1). Larger families meant more hands to assist with the task of caregiving, thus alleviating the severity of the stressor and promoting family adaptation. However, 33% of the participants in the child subgroup suffered from social isolation. These participants mentioned that friends were less likely to visit due to the condition of the dementia patient, and that their caregiving responsibilities made it very difficult to leave the house for socialisation. The impact of social isolation was not found in the spouse subgroup at all (see Table 5.5). The importance of informal support from family and friends is mirrored in several studies on family resilience. The qualitative results in the studies by Greeff and Thiel (2012), Greeff and Wentworth (2009) and Preece and Sandberg (2005) identify emotional intra-familial support as a major feature in the family's adaptation process. The buffering effect of support from family and friends on burden in dementia caregivers is also echoed in several studies (Losada et al., 2010; Mitrani & Czaja, 2000; Quinn et al., 2008; Yamashita & Amagai, 2008; Zarit, 2008). Furthermore, Haley et al. (1987) found that caregivers with more friends and close relationships and who more often participated in social activities with friends reported higher levels of overall life satisfaction. These variables were also related to better health outcomes in both dementia caregivers and patients. In accordance with the qualitative findings of the current study, Quinn et al. (2008) found that social isolation is common in dementia caregivers. Due to the demanding nature of dementia care, many caregivers withdraw from activities and interests.

Other caregivers felt that they were invited out less by their friends. Nonetheless, these caregivers valued the support provided by friends and family.

The results obtained with the Social support subscale of the F-COPES, which measured the family's willingness to seek out social support from relatives, friends, neighbours and extended family, had no correlation with family adaptation in either family subgroup (see Table 5.2). Furthermore, no statistically significant correlation was found between family adaptation and relative and friend support (RFS total score) in any of the family subgroups. Nevertheless, a tendency was noticed in the child subgroup that suggested a possible relationship between the variables family adaptation and relative and friend support (RFS total score). The best subset of the regression analysis of the spouse subgroup included relative and friend support as a predictor of family adaptation. However, the contribution of relative and friend support to variance in family adaptation was not significant. Furthermore, this variable was only present in seven (35%) of the 20 best subsets, thus suggesting that the inclusion of this variable in the best subset could possibly be due to chance (see Figure 5.7b). The quantitative results were thus unable to verify the qualitative findings identifying family and friend support as a key family resilience resource. Similar results were found by Greeff and Thiel (2012). The qualitative results in their study identified emotional and practical support from family members as the most important internal resilience factor in family adaptation. However, no significant correlations were found in the quantitative data to support these findings. The importance of family and friend support was, however, recognised in other family resilience studies. Bester (2009) found a statistically significant correlation between relative and friend support and family adaptation in the children subgroup. No significant correlations were found in the spouse subgroup, however. Carnes and Quinn (2005) found that social support, as measured by the F-COPES, had a significant positive correlation with both increased family functioning and decreased psychological distress. These findings were supported by the regression analysis, which identified social support as a significant predictor of family functioning. Jonker and Greeff (2009) found no significant correlation between family adaptation and friend and relative support. In contrast to other studies, however, the regression analysis identified friend and relative support as a negative predictor of family adaptation. This finding was not supported by the qualitative data, or by the

Spearman correlations. Jonker and Greeff (2009) attributed these findings to the study's small sample size or to possible problems in the statistical analysis.

The family subgroups in this study differed in terms of the importance with which they valued community support. In the spouse subgroup, 42% of the participating families used community support to help them adapt to their situation. On the contrary, only 14% of the participants from the child subgroup mentioned community support as an effective resilience resource. The families in the spouse subgroup also deemed support from religious institutions as an important resilience resource that provided them with emotional support when the burden of dementia care got too much to handle. Prayer groups and church services promoted spirituality, which provided family members with an internal strength that acted as a buffer against adversity. Church activities also acted as a social avenue through which the family members of the dementia patient could take a break from the troubles at home and just relax with other churchgoers. One participant mentioned that the church provided care packages containing food to families in need. Nonetheless, the effect of support from religious institutions was only mentioned by 5% of the child subgroup. On the contrary, the child subgroup more often made use of hired help. In the child subgroup, 62% of the participants mentioned the positive impact of hired help on family adaptation. Hired help included nurses or dementia caretakers hired by the family, elderly day-care facilities, or respite care where families could drop off dementia patients for a few nights. Families used these services as a way to take a break from their continuous caregiver responsibilities. These services were only mentioned by 32% of the participants of the spouse subgroup. Support from others facing similar problems was mentioned by 37% of the spouse subgroup and 33% of the child subgroup. Organisations like Alzheimer's South Africa or Dementia South Africa host informational sessions and support groups in which the family members of dementia patients can talk to other caregivers in the same situation. Despite these findings, 33% of the spouse subgroup and 43% of the child subgroup struggled to find sources of community support.

The positive effect of community support on the carers for dementia patients has been emphasised by several studies. Haley et al. (1987) found a significant positive correlation between church attendance and life satisfaction. The impact of religious

or congregational affiliations on family resilience has been discussed in Walsh's (2002, 2003) Resilience Framework. Zarit (2008) also identified paid respite services, like adult day services and in-home carers, as a helpful community resource that allowed family members to take a break from their caregiving responsibilities or to carry out other important activities. Both Quinn et al. (2008) and Zarit (2008) identified voluntary organisations, like the Alzheimer's Association or the Alzheimer's Society, as beneficial community support resources for dementia caregivers.

The quantitative results support the qualitative findings regarding community support. Family adaptation tended to be better in families who were better integrated into their community, who more often found support in their community; and who regularly made use of community resources when caring for a family member with dementia (as measured by the SSI) (see Table 5.2). The regression analysis on the data of the spouse subgroup identified the degree to which families found support in their community (SSI: Total) as a predictor of the variance in family adaptation (see Table 5.3). Even though its contribution was not statistically significant, this variable was present in all of the 20 best regression subsets, thus validating its contribution to family adaptation. In the multiple regression analysis of the child subgroup's data, both the degree to which families found support in their community (as measured by the SSI total score) and the mobilisation of the family to seek and accept help from others (as measured by the Mobilisation subscale of the F-COPES) were identified in the best-subset regression as predictors of the variance in family adaptation. However, the contribution of these variables to variance in family adaptation was not statistically significant, and both were present in only nine (45%) of the 20 best regression subsets (see Figure 5.7b). It thus is possible that these variables were only included in the best subset due to chance. Greeff and Wentworth (2009) also found a statistically significant correlation between family adaptation and the support found by families in the community. Similar results were found in the children subgroup of Greeff et al.'s (2006) study. The relationship between family adaptation and support from within the community also seemed important to Greeff et al.'s (2006) parent subgroup, but this finding was not statistically significant. However, both the quantitative and qualitative results of Jonker and Greeff (2009) found that the relationship between family resilience and the family's ability to seek out and

utilise community resources was relatively insignificant. Similar results were found in the Japanese study by Yamashita and Amagai (2008), in which seeking help from outside the family was not in agreement with the societal expectations of families. Caregivers believed that they were abandoning their caregiving responsibilities if they made use of external support structures and thus avoided community support.

The final community resource identified in this study was the support provided by professional service providers, like doctors, psychologists and social workers. In the current study, 29% of the child participants and 32% of the spouse participants felt that the information provided by medical doctors was crucial in helping them understand the diagnosis of the patient (see Table 5.5). However, the use of other professional support, like help from therapists, was not very common. No connection was found between mobilising professional support and family adaptation in the quantitative results. The family's ability to accept help from others (for example professional help or the use of community resources), as measured by the Mobilisation subscale of the F-COPES, had no significant correlations with the FACI8 scores, which measured family adaptation. The qualitative results in Greeff et al.'s (2006) study revealed a positive relationship between the mobilisation of help and family adaptation, but no statistically significant relationship between these variables was found in the quantitative results. Greeff and Thiel (2012) found that medical doctors made a positive impact on resilience in families with a husband diagnosed with prostate cancer. According to these authors, medical professionals are usually the family's first source of information after the diagnosis of the patient and, as experts in the field, they could provide caregivers with sound advice regarding the effective management of the illness. Zarit (2008) supports this view and explains that the support received from physicians and other healthcare providers has a significant effect on the quality of care the patient received and ultimately improves the quality of the caregivers' lives. Preece and Sandberg (2005) have suggested marital and family therapy as a fitting treatment approach to help families in which a family member was diagnosed with FMS to manage the familial problems commonly associated with the illness. Davis (1997) found that professional services like family counselling and family-level skills training alleviated caregiver burden in the family caregivers of dementia patients. Furthermore, family-based

psycho-educational interventions increased support and participation from family members in dementia home-care, which in turn buffered caregiver burden.

6.4.4 Economic resources

Economic resources were not a prominent theme in the qualitative findings. Most of the participants in the child subgroup (62%) felt that they were doing fine without any financial support. This was mentioned by 37% of the spouse subgroup. The families who made use of financial support got financial backing from family members. None of the financial support was provided by government. Only one participant elaborated on this aspect, explaining that the costs of treatment and medication – which are not covered by any medical aid – put immense financial strain on the family. None of the participants elaborated on financial stability as a resilience resource. This finding could be attributed to the way the qualitative question was stated. Family representatives were asked whether their family made use of any financial support structures to help them adapt to their situation. It is thus possible that family representatives only focused their thoughts on external financial support and neglected any thoughts regarding the effect of their own financial security on their family's adaptation.

The importance of financial stability was apparent in the quantitative results of the child subgroup, which revealed a significant positive relationship between the household income and family adaptation (see Table 5.1). This implies that families who were more financially secure tended to show more signs of family adaptation than families with lower household incomes. However, these results were not found in the spouse subgroup. The difference between the subgroups regarding the impact of financial stability on family resilience could be due to the difference in size of the households in the different subgroups. An ANOVA comparing the number of adults living in the household revealed that the child subgroup tended to have more family members in the household than the spouse subgroup. A larger household income is thus needed to provide for a larger number of household members. The effect of financial strain could thus be more noticeable in these families.

Studies on family resilience show that good financial management and a satisfactory economic status have a positive relationship with family well-being. Families who

have adequate economic resources do not have to deal with the pile up of stressors connected with poverty, like unemployment, substandard housing and a lack of health care, which contributes to family adaptation when facing adversity (Black & Lobo, 2008; Walsh, 2003). Both the qualitative and quantitative results of Carnes and Quinn's (2005) study showed a positive relationship between financial security and family functioning, a negative relationship between financial security and psychological distress, and a positive relationship between financial security and family adaptation. Furthermore, concerns regarding insurance coverage were connected to psychological distress and lower family functioning, which hindered the family resilience process. In contrast, Greeff and Wentworth (2009) and Greeff et al. (2006) found no significant correlation between family adaptation and the family's income. Greeff and Wentworth (2009) attribute this finding to the financial stability of the participants in their study, who were either gainfully employed or had made adequate provision in terms of medical aid, thus enabling them to meet the expenses of adequate medical services. Pattanayak et al. (2010), who studied the various areas and predictors of burden in dementia caregivers, also found no significant relationship between caregiver burden and income.

6.5 Communication and Problem-solving Processes

The qualitative data in the current study showed that 68% of the participants in the spouse subgroup and 76% of the participants in the child subgroup deemed communication as a crucial factor in the resilience process (see Table 5.5). The importance of positive communication patterns was emphasised by more than half of the participants in the child subgroup. These participants explained that the adaptation of the family as a unit was easier if family members were open about the prognosis of the illness and shared their experiences and knowledge with each other. As a result, family members were better able to understand the illness and thus deal effectively with behaviour of the patient. Furthermore, it fostered an understanding between family members as they were aware of each other's feelings and thus better able to support each other on an emotional level. In addition, more than half of the participants in both subgroups identified patience as a vital characteristic that was essential when living with a dementia patient. Participants explained that the nature of the illness tested one's patience and that it was common

to become frustrated or lose one's temper when subjected to the continuous burdens associated with this illness. However, the participants emphasised that negative communication patterns, like shouting and screaming, were ineffective ways of dealing with the issues and that they were better able to cope with a situation once they had calmed themselves.

These findings enjoy theoretical support; the Family Resilience Framework proposed by Walsh (2002, 2003) identifies open, honest communication that encourages collaborative problem solving and conflict management as a key factor in the family resilience process. Members of well-functioning families openly discuss their own ideas regarding adverse conditions and encourage other family members to do so as well. They keep each other informed as the situation develops and use failure as a learning experience when trying to adapt to the situation. Furthermore, they listen to, understand and respect each other's opinions, even when they are in disagreement. These families also tend to discuss the emotional impact of adverse conditions and support each other as the situation progresses. Families who are unable to share these emotions with each other often have to deal with negative outcomes, like depression and relational conflict (Black & Lobo, 2008; McCubbin & McCubbin, 1996; Walsh, 2003). The connection between positive communication and adaptation is supported by several studies on buffering the burden in dementia caregivers. Zarit (2008) explains that open, clear communication on the problems involved in dementia care often promotes a better understanding of dementia in the whole family, thus lowering intra-family conflict, promoting intra-familial support, and ultimately buffering caregivers against the burdens of dementia caregiving. Davis (1997) and Mitrani and Czaja (2000) also emphasise positive communication patterns between family members when caring for a family member with dementia. Both studies found that family caregivers of dementia patients effectively have to resolve intra-familial conflict to minimise caregiver burden. Clear, direct communication is encouraged when dealing with disagreements and/or criticisms and families have to learn how to manage differences of opinion without personal attacks. Families can only function effectively as a problem-solving entity if the family members are able to put aside their existing differences and effectively negotiate caregiving activities that are acceptable to all the parties affected by the decision.

The quantitative findings supported the qualitative findings on the effect of communication on family resilience. Family problem-solving communication patterns had a strong, statistically significant positive correlation with family adaptation in both family subgroups (see Table 5.2). In addition, family adaptation in both family subgroups had a strong, positive correlation with communication patterns that conveyed support and care (as measured by the Affirming communication subscale of the FPSC) and a strong, statistically significant negative correlation with negative, provocative communication patterns (as measured by the Incendiary communication subscale of the FPSC). These findings were supported in the best-subset regression analysis. In both the spouse and child subgroups, the family's overall problem-solving communication patterns were identified as the independent variables that best predicted variation in family adaptation. Furthermore, the contribution of the FPSC total score in the FACI8 total score (which measures family adaptation) was statistically significant for both the spouse and child subgroups (see Tables 5.3 and 5.4). In both family subgroups, the family's overall problem-solving communication patterns were present in all of the 20 best subsets, thus validating the significant contribution of this variable in predicting family adaptation (see Figure 5.7a and 5.7b).

Several studies on family resilience (Bester, 2009; Greeff & Thiel, 2012; Greeff & Wentworth, 2009; Jonker & Greeff, 2009) mirror these findings. In these studies, a significant positive correlation was found between family adaptation and the family's overall problem-solving communication patterns. The results of the FPSC subscales support this finding; positive, supportive communication patterns (as measured by the Affirming subscale of the FPSC) have a strong, statistically significant positive correlation with family adaptation, while negative, inflammatory communication patterns (as measured by the Incendiary subscale of the FPSC) have a strong, statistically significant negative correlation with family adaptation (Bester, 2009; Greeff & Thiel, 2012; Greeff & Wentworth, 2009; Jonker & Greeff, 2009). Patterson (2002b) also identified affective communication patterns, through which family members express love and support for each other, as a crucial resilience resource that facilitates family adaptation.

6.6 Individual Characteristics of Family Members

The characteristics of individual family members were identified as resilience resources by 43% of the child subgroup and 37% of the spouse subgroup (see Table 5.5). Specific characteristics mentioned were primary caregiver's past experience in caregiving, friendliness, inner strength, and the use of avoidance coping strategies. In the current study, the age and gender of the caregiver and the patient seemed to have a significant effect on family adaptation. However, these findings were only evident in the responses of the spouse subgroup. Jonker and Greeff (2009), Greeff and De Villiers (2008) and Greeff and Thiel (2012) also found that the characteristics of individual family members had a positive effect on the family resilience process.

6.7 Conclusion

In this chapter, the results obtained in the current study were compared with the literature that focused on similar themes. Several family resilience resources were identified that suggested possible avenues for intervention that could facilitate the adaptation of families living with a family member diagnosed with dementia.

Firstly, adaptation in families living with a family member with dementia can be supported by implementing interventions designed to promote positive communication and problem-solving strategies within the family. The quantitative results of both family subgroups revealed that family adaptation tended to be better in families with a higher total score in the FPSC, higher scores on the Affirming Communication Subscale of the FPSC, and lower scores on the Incendiary Communication Subscale of the FPSC. However, the family subgroups differed with regard to their communication patterns. The ANOVA comparing the quantitative results of the family subgroups revealed that children caring for a parent diagnosed with dementia scored lower on the affirming communication subscale of the FPSC and higher on the incendiary communication subscale of the FPSC than spouses caring for their partners. Conversely, only 26% of the spouse subgroup mentioned open communication patterns as a resilience resource in the qualitative interview, while it was mentioned by more than half of the child subgroup. To optimise family adaptation, intervention strategies that focus on communication thus need to be tailored to the different needs of these subgroups.

Secondly, families living with a family member with dementia need to be supported in their acceptance of the diagnosis. The results of both family subgroups revealed that family resilience was significantly affected by the family's subjective appraisal regarding the severity of the illness, which was generally evaluated in terms of the family's ability to effectively manage the dementia symptoms. Several participants explained that adaptation could only take place once the diagnosis had been accepted. Family-based caregiver training that focuses on dementia, the problems associated with dementia, and strategies for the management of these problems could thus facilitate family adaptation processes. This study revealed that children caring for their parents diagnosed with dementia identified information-seeking as a resilience resource more often than spouses caring for their partners diagnosed with dementia. Interventions targeting the spouses of dementia patients should thus consider including information sessions in the programme to fully inform these families about the illness and its problems.

Thirdly, the current study revealed that family adaptation in families caring for a family member diagnosed with dementia was facilitated by social support. Family connectedness and intra-familial support were deemed very important resilience characteristics by both family subgroups. Furthermore, both family subgroups identified informal support from extended family and friends as an important support structure that helped them adapt. The spouse subgroup made use of several other support structures as well. Community support seemed to play a very important role in these families. Despite the positive correlation between family adaptation and community support, the child subgroup made very little use of community support. The quantitative results even showed that connection with relatives outside the household did not show a significant relationship with family adaptation in the child subgroup. The only participants who mentioned social isolation were in the child subgroup, thus establishing a need for more social support in families from this subgroup. These families need to be encouraged to make use of community support. Community support programmes that target these families could have a positive influence on their family adaptation. Another problem that seemed common among both groups was the lack of information regarding community support. Intervention strategies should thus ensure that information regarding support avenues is easily accessible.

In addition, the utilisation of hired help should be advocated – especially in families where spouses care for their partners diagnosed with dementia. Few participants in the spouse subgroup utilised hired help when caring for their partner diagnosed with dementia, while the majority of the participants from the child subgroup used hired help. Furthermore, the results show that the age of the caregiver tended to be a significant risk factor in the spouse subgroup. Spouses who take on the role of primary caregiver often have to deal with their own health problems as well. Prior studies show that family caregivers of dementia patients often neglect their own health, thus increasing the risk for future health problems (e.g. Albinsson & Strang, 2003; Heru & Ryan, 2006; Majerovitz, 1995; Marquez-Gonzalez et al. 2007; Mitrani & Czaja, 2000; Pattanayak et al., 2010; Quinn et al., 2008; Zarit, 2008). Health problems thus often hinder the ability of spouses to effectively manage the symptoms of the dementia patient. This pile up of stressors could have a negative effect on family adaptation, explaining the negative correlation between the caregiver's age or the patient's age and family adaptation in the spouse subgroup. The caregiving role can be simplified by the utilisation of professional carers who take over the physical burdens of dementia care.

A significant positive relationship between the household income and family adaptation was only evident in the child subgroup. These results could be attributed to the larger number of family members residing in these households. The child subgroup tended to have more family members in the household than the spouse subgroup, thus necessitating a larger household income is to provide for them. The effect of financial strain could thus be more noticeable in these families. Intervention strategies that focus on financial planning could facilitate adaptation in these families. Public policies assisting families caring for family members with dementia could also have a positive influence on their adaptation.

Finally, optimism seems to be a vital characteristic in resilient families. The quantitative results revealed that family hardiness was significantly correlated with family adaptation in both subgroups. However, different strategies for maintaining a positive attitude were utilised by the different subgroups. Passive appraisal as a coping strategy had a significant, positive relationship with family adaptation in the child subgroup. Conversely, reframing a crisis situation had a significant, positive

correlation with family adaptation in the spouse subgroup. Although the majority of both family subgroups revealed in the qualitative results that they actively sought out methods to help them retain a positive attitude, the child subgroup mentioned this coping strategy more often than the spouse subgroup. However, more families from the spouse subgroup mentioned spirituality as a source of hope than families from the child subgroup. Nonetheless, intervention strategies that promote family hardiness and improve optimism in the family unit could have a positive influence on family resilience in both family subgroups.

6.8 Limitations and Suggestions for Future Research

This study has provided some important insights regarding resilience factors in families living with a family member diagnosed with dementia. However, there were several limitations to this study. Firstly, this study was conducted using a cross-sectional survey design. Data collection consisted of the once-off gathering of data at a single point in time, thus ignoring the families' adaptation levels before the patient was diagnosed with dementia. However, in the Resilience Framework proposed by Walsh (1996, 2002, 2003), family resilience is described in terms of a developmental perspective that emphasises the ongoing, adaptive and evolving nature of family resilience. As the family system moves forward over time, families constantly evaluate their level of functioning. How problems were managed in the past has a significant influence on future expectations regarding family adaptation. Considering the degenerative nature of the illness, the adaptation of the family unit as the dementia progresses is of great importance. Future researchers should thus consider longitudinal studies that compare family adaptation at different stages of the illness, including pre-diagnosis. This comparison would convey a better description of the family's level of adaptation, and thus provide a more accurate representation of the resilience resources that helped them to reach a state of balance and harmony.

Secondly, the participating families in the present study were represented by one family member who had to convey the opinions and thoughts of the entire family unit. The personal biases of the family representative could have had a negative influence on the validity of the results. The trustworthiness of the results can be enhanced by making use of triangulation, in which data is gathered from several family members

from the same family unit. The credibility of the study could be improved even more by including a third party in the data collection process, like a house doctor or part-time nurse who knows the family well.

A third limitation of this study was the small sample sizes of the subgroups. The influence of a single participant's responses on the total findings of the study increases significantly as the sample size decreases. As a result, the overall power of the results decreases, thus increasing the probability of making type II errors in the quantitative data analyses. Future research can improve on this study by recruiting a larger participant group.

Furthermore, there were some limitations regarding the demographic distribution of the participants. Due to the convenience sampling strategy used, the two subgroups in this study (spouse and child) were not matched in terms of the participants' age, race, income or level of education. Minor differences in these variables could contribute to differences found between spouses caring for their partners diagnosed with dementia and adult children caring for their parents diagnosed with dementia. In addition, the racial and gender distribution was not equally representative in the sample. The majority of the participants were either white or coloured and had English or Afrikaans as their first language. Only 5% of the participating families were black. As a result, the findings of the study cannot be generalised to other cultural groups in South Africa. Some gender bias could also be present in the results, since 75% of the participants were women. A sample that better represents the South African population in terms of race and gender should be used in future studies. Furthermore, the generalisability of the study findings can be improved by matching the groups that will be compared in terms of their demographic information.

In addition, the participants often found it difficult to answer some of the items in the quantitative questionnaires due to the ambiguity of the word "family" as a concept. This was mostly evident in the spouse subgroup, who often viewed their adult children as part of the household, even though they no longer lived with them. During the data collection process, the researcher attempted to clarify most of the ambiguous statements in the measures, but since the quantitative measures used in this study were completed by the participants themselves, the degree to which they

fully understood the items and correctly answered them is unclear. Future studies should thus include a detailed description of the central concepts (e.g. “family”) in the quantitative measures.

Finally, the quantitative measures used in this study had some limitations. The FHI Control subscale, which measures the family’s perception of control regarding their own life, and the FTRI Family time together subscale, which measures the family’s emphasis on predictable routines that encourage togetherness, both obtained low internal reliability coefficients in the current study. Future studies should make use of data collection strategies that can improve the internal reliability of these measures, or make use of a more reliable quantitative measure to assess the target variables. As mentioned earlier, no significant correlation was found between spiritual and religious support as a coping strategy and family adaptation, even though the majority of the participants mentioned this aspect in the qualitative interview. These results could possibly be attributed to the nature of the items of the F-COPES: Spiritual support subscale, which was used to measure the variable. The F-COPES: Spiritual support subscale neglects the spiritual support provided by spiritual rituals practised in private, or in the family unit (e.g. prayer, meditation, family Bible study). Future studies should thus explore the influence of spiritual support on family resilience using a quantitative scale that better measures the different facets of spirituality. Similar problems were present in the FTRI, which measured the routines utilised by the families. In the literature review it was found that family members who care for dementia patients employ routines that simplify their caregiving tasks. The FTRI, which focuses mostly on the routines connected to children in the household, does not take these caregiving routines into consideration. A quantitative measurement that assesses these routines could thus yield more accurate results on the impact of routines on family adaptation. Some qualitative findings could not be validated quantitatively due to a lack of measures that assess these variables. Firstly, the severity of the dementia symptoms should be evaluated using an objective measuring instrument. By comparing these results with those obtained with the FACI8, the nature of the relationship between the objective severity of the illness and family adaptation could be explored in more detail. Secondly, the subjective appraisal of the dementia symptoms, as well as the presence of other, additional stressors, should be measured quantitatively and compared to the family’s level of

adaptation. This could improve our understanding of subjective appraisal in the resilience process.

Future researchers should attend to these limitations in order to obtain a better understanding of the resilience qualities utilised by families living with a family member diagnosed with dementia.

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ADDENDUMS

Addendum A: Letter from Supervisor



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jou kennisvennoot • your knowledge partner

Dear Mr/Ms

Research undertaken by Melanie Deist (Student nr. 15080064)

Melanie is currently busy with her Masters thesis in the Department of Psychology, University of Stellenbosch. She has just started with her research proposal regarding family resilience qualities in families caring for a family member diagnosed with dementia. As her research supervisor, I suggested to her to get preliminary permission to make (at a later stage) contact with families of patients diagnosed with dementia. Once she has your approval, she will finalise her research proposal and obtain ethical clearance from the University's Ethical Committee. I want to confirm that Ms Deist will adhere to the ethical principles required by the profession.

To add, the focus of the research is on family qualities/characteristics that help them to make the necessary changes to adapt and continue with life. The diagnosed patient will not take part in the data collection process. Previous, similar research in other family populations were experienced as positive by participants and in many instances actually helped the families to start thinking about their strengths and resources.

In summary, at this stage we would like to have the support of your organisation with regard to identifying families as indicated. Once Ms Deist's research proposal is finalised, she will apply for ethical clearance. Only then will she approach you again to help her to identify families and make contact with them as stipulated in her research proposal and ethical clearance application. Please feel free to contact me should you want more clarity.

Thanks in advance.

Yours sincerely

AP Greeff (Supervisor)



Departement Sielkunde • Department of Psychology

Addendum B: Agreement to help identify participants**Assistance**

I was approached by Melanie Deist who asked for my assistance to help her identify possible participants for her Masters thesis on resilience characteristics that are present in families where family members are caring for a patient diagnosed with dementia. The nature of the research was explained to me and I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby agree voluntarily to assist Ms Deist in identifying possible participants for her study once she finalised her research proposal and obtained ethical clearance from Stellenbosch University's Ethical Committee.

Dementia SA

Name of Organization

Bobby Tuten

Name of representative

[Signature]
Signature of representative

23 February 2011

Date

Note: This form does not force you to assist in this study and is in no way legally binding. You may withdraw your offer of assistance at any time - even after the form has been signed.

Assistance

I was approached by Melanie Deist who asked for my assistance to help her identify possible participants for her Masters thesis on resilience characteristics that are present in families where married children are caring for a parent diagnosed with dementia. The nature of the research was explained to me and I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to assist Ms Deist in identifying possible participants for her study once she finalised her research proposal and obtained ethical clearance from Stellenbosch University's Ethical Committee.

Alzheimer's SA - Western Cape.
Name of Organization

Jim Robson.
Name of representative


Signature of representative

17.2.2011.
Date

Note: This form does not force you to assist in this study and is in no way legally binding. You may withdraw your offer of assistance at any time - even after the form has been signed.



T (021) 930 2177 F (021) 930 2178
48 Hennie Winterbach Str, Panorama, 7500
www.gomemory.co.za

2012-02-21

Ms Melanie Deist

RESEARCH PROTOCOL: Resilience Factors of Families Caring for a Family Member Diagnosed with Dementia

You are hereby granted permission to proceed with your research at the support group meetings hosted by our practice at the Panorama Medi Clinic, on specified dates.

Please note the following;

- The contact details of families and caregivers showing interest in participating will be made available to you. Thus, you may only contact the list of consenting participants
- Your research may not interfere with normal patient care
- Staff may not be asked to assist with the research
- Only you are permitted to gather information from families and caregivers
- Please introduce yourself and your research program to the families and caregivers
- Offer feedback on the research results to participants who requested it

Yours sincerely

Dr Michael S Mason
PSYCHIATRIST

Anton Bohmer
CLINICAL PSYCHOLOGIST

Dr Azelle A Mayne, Dr Michael S Mason, Dr Paul R Magni, Dr Elsa du Toit,
Gustav Van Greunen, Monique Green, Sandra Hitchcock, Anton Böhmer



DIRECTORATE: HEALTH
Groote Schuur Hospital
Enquiries: Dr Bhavna Patel
E-mail : Bhavna.Patel@gowc.gov.za

Ms Melanie Deist
c/o Professor John Joska
Department of Psychiatry
J-block

E-mail: John.Joska@uct.ac.za

Dear Ms Deist

RESEARCH PROTOCOL: Resilience Factors of Families Caring for a Family Member Diagnosed with Dementia

Your recent letter to the hospital refers.

You are hereby granted permission to proceed with your research.

Please note the following:

- a) Your research may not interfere with normal patient care
- b) Hospital staff may not be asked to assist with the research.
- c) No hospital consumables and stationary may be used.
- d) No patient folders may be removed from the premises or be inaccessible.**
- e) Please introduce yourself to the person in charge of an area before commencing.

I would like to wish you every success with the project.

Yours sincerely

A handwritten signature in cursive script, appearing to read "B Patel".

DR BHAVNA PATEL

SENIOR MANAGER: MEDICAL SERVICES

Date: 15th February 2012

Addendum C: Flyers

Are you currently living with a family member diagnosed with dementia?

You may be eligible to participate in a study conducted by
Stellenbosch University*

Only 1 hour of your time is needed. The study involves:

- A short interview with the researcher
- Completing a few questionnaires

Your participation will help us understand which family characteristics help families to cope with their situation when caring for a family member diagnosed with dementia.

For more information contact Melanie Deist at:

Cell: 084 469 3503

Email: mel.deist@gmail.com

Leef u tans saam met 'n familielid wat met demensie gediagnoseer is?

U kan deelneem in 'n studie wat uitgevoer word deur
Stellenbosch Universiteit *

Slegs 1 uur van u tyd word benodig. Die studie behels die volgende:

- 'n Kort onderhoud met die navorser
- Die voltooiing van 'n paar vraelyste

U deelname kan lig werp op daardie familie kenmerke wat gesinne, wat tans sorg vir 'n familielid met demensie, help om aan te pas by hul situasie.

Vir meer inligting, kontak Melanie Deist by:

Sel: 084 469 3503

E-pos: mel.deist@gmail.com

Addendum D: Contact details form



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvennoot • your knowledge partner

RESILIENCE IN FAMILIES CARING FOR A FAMILY MEMBER DIAGNOSED WITH DEMENTIA

Good day

You are invited to participate in a research project conducted by Melanie Deist through the Faculty of Arts and Social Sciences at the University of Stellenbosch. This study forms part of Ms Deist's Masters dissertation and explores the characteristics and resources families, who are currently taking care of a family member diagnosed with dementia, use in an attempt to adapt to their situation.

We are currently looking for volunteers to participate in this study.

Only 1 hour of your time is needed.

The study involves: 1) a short interview with the researcher; and 2) completing a few questionnaires

If you are willing to help out, please fill in your details below and we will contact you as soon as possible.

[illegible]

Addendum E: Biographical Questionnaire

All information in this questionnaire is strictly confidential and your information will be processed anonymously.

Please cross the box most appropriate to **you**, or complete the statement in the space provided:

1. Living in (Town or city)

2. Race

☐ White ☐ Coloured ☐ Black ☐ Other

3. Home language

☐ Afrikaans ☐ English ☐ Other

4. What is your family's estimated gross income **per month**?

☐ Less than R1 000 ☐ R1 000 – R2 000 ☐ R2 001 – R5 000
☐ R5 001 – R10 000 ☐ R10 001 – R15 000 ☐ More than R15 000

5. Family composition

a. Please tick the box which best describes your **current** marital status

☐ Single ☐ Cohabiting
☐ Married ☐ Widowed
☐ Divorced ☐ Other

b. How many times had you been married? And your partner?

c. For how long have you been married to your current partner? Years

d. How many adults live in your home?

For each of the adults in your home, excluding the patient, please try to answer the following:

		Gender <i>(Male / Female)</i>	Level of education <i>(None / Primary School / High School / Diploma / Degree / Other)</i>	Employed <i>(Yes/No)</i>	Relationship to patient <i>(Spouse / Child / Sibling, etc.)</i>
Adult 1 (self)					
Adult 2					
Adult 3					
Adult 4					
Adult 5					
Adult 6					

e. How many children live in your home?

For each of the children in your home, please try to answer the following:

	Age	Gender <i>(Male / Female)</i>	Relationship to patient <i>(Grandchild / Child etc.)</i>
Child 1			
Child 2			
Child 3			
Child 4			
Child 5			
Child 6			

6. Patient information

a. Age

b. Gender ☐ Male ☐ Female

c. Cause of dementia (*Alzheimer's/ Vascular Dementia / Tumour, etc.*)

d. When was the patient first diagnosed with dementia?

☐ 1-2 years ago ☐ 2-4 years ago ☐ 4-6 years ago

☐ More than 6 years ago

Biografiese Vraelys

Alle inligting in hierdie vraelys word as streng vertroulik beskou en u besonderhede sal anoniem verwerk word.

Merk asseblief die toepaslike blokkie, of verskaf die verlangde inligting:

1. Woonagtig in (*Dorp of Stad*)

2. Ras

☐ Wit ☐ Kleurling ☐ Swart ☐ Ander.....

3. Huistaal

☐ Afrikaans ☐ Engels ☐ Ander

4. Wat is u gesin se geskatte bruto inkomste per maand?

☐ Minder as R1 000 ☐ R1 000 – R2 000 ☐ R2 001 – R5 000
☐ R5 001 – R10 000 ☐ R10 001 – R15 000 ☐ Meer as R15 000

5. Gesinsamestelling

a. Merk die blokkie wat u huidige huwelikstatus die beste beskryf

☐ Enkellopend ☐ Woon Saam
☐ Getroud ☐ Weduwee/Wewenaar
☐ Geskei ☐ Ander

b. U hoeveelste huwelik is hierdie? En u eggenoot?

c. Hoe lank is u nou al met u huidige maat getroud? jare

d. Hoeveel volwassenes bly in u huis?

Vir elke volwassene in u huis, uitsluitend die pasiënt, voltooi asseblief die volgende:

	Ouderdom	Geslag (Manlik / Vroulik)	Kwalifikasie (Geen / Laerskool / Hoërskool / Diploma / Graad / Ander)	Werk (Ja / Nee)	Verhouding met pasiënt (Eggenoot / Kind / Broer/ Suster, ens.)
Volwasse 1 (self)					
Volwasse 2					
Volwasse 3					
Volwasse 4					
Volwasse 5					
Volwasse 6					

e. Hoeveel kinders bly in u huis?

Vir elke kind in u huis, voltooi asseblief die volgende:

	Ouderdom	Geslag (Manlik / Vroulik)	Verhouding met pasiënt (Kleinkind / Kind, ens.)
Kind 1			
Kind 2			
Kind 3			
Kind 4			
Kind 5			
Kind 6			

6. Pasiënt inligting

a. Ouderdom

b. Geslag ☐ Manlik ☐ Vroulik

c. Oorsaak van dementia (*Alzheimer's/ Vascular Dementia /Kanker, ens.*)

d. Wanneer was die pasiënt vir die eerste keer gediagnoseer met dementia?

☐ 1-2 jaar terug ☐ 2-4 jaar terug ☐ 4-6 jaar terug
☐ Meer as 6 jaar terug

Addendum F: Quantitative Questionnaires**1. Family Attachment Changeability Index 8 (FACI8)**

INSTRUCTIONS : Decide how well each statement describes what is currently happening in your family and circle the number which best describes how often each thing is currently happening.

In my family...	Never	Sometimes	Half the time	More than half	Always
In our family it is easy for everyone to express his/her opinion.	1	2	3	4	5
It is easier to discuss problems with people outside the family than with other family members.	1	2	3	4	5
Each family member has input in major family decisions.	1	2	3	4	5
Family members discuss problems and feel good about the solutions.	1	2	3	4	5
In our family everyone goes his/her own way.	1	2	3	4	5
Family members consult other family members on their decisions.	1	2	3	4	5
We have difficulty thinking of things to do as a family.	1	2	3	4	5
Discipline is fair in our family.	1	2	3	4	5
Family members feel closer to people outside the family than to other family members.	1	2	3	4	5
Our family tries new ways of dealing with problems.	1	2	3	4	5
In our family, everyone shares responsibilities.	1	2	3	4	5
It is difficult to get a rule changed in our family.	1	2	3	4	5
Family members avoid each other at home.	1	2	3	4	5
When problems arise, we compromise.	1	2	3	4	5
Family members are afraid to say what is on their minds.	1	2	3	4	5
Family members pair up rather than do things as a total family.	1	2	3	4	5

INSTRUKSIES : Besluit hoe goed elke stelling beskryf wat in u gesin gebeur. Omkring die nommer wat die beste beskryf hoe gereeld elke stelling huidiglik (m.a.w, nou) gebeur.

In my gesin...	Nooit	Soms	Helfte van kere	Meer as helfte	Altyd
In ons gesin is dit vir almal maklik om sy/haar opinie te gee.	1	2	3	4	5
Dit is makliker om probleme met mense buite die gesin as met ander gesinslede te bespreek.	1	2	3	4	5
Elke lid van die gesin het 'n sê in belangrike gesinsbesluite.	1	2	3	4	5
Gesinslede bespreek probleme en voel goed oor die oplossings.	1	2	3	4	5
In ons gesin doen elkeen sy/haar eie ding.	1	2	3	4	5
Lede van die gesin beraadslaag met ander gesinslede oor hul besluite.	1	2	3	4	5
Ons vind dit moeilik om aan dinge te dink wat ons as 'n gesin kan doen.	1	2	3	4	5
Dissipline is regverdig in ons gesin.	1	2	3	4	5
Gesinslede voel nader aan mense buite die gesin as aan ander gesinslede.	1	2	3	4	5
Ons gesin beproef nuwe maniere om probleme te hanteer.	1	2	3	4	5
In ons gesin deel almal verantwoordelikhede.	1	2	3	4	5
In ons gesin is dit moeilik om 'n reël te verander.	1	2	3	4	5
Gesinslede vermy mekaar by die huis.	1	2	3	4	5
Wanneer probleme ontstaan, kom ons tot 'n vergelyk.	1	2	3	4	5
Gesinslede is bang om te sê wat hulle op die hart het..	1	2	3	4	5
Gesinslede paar af eerder as om dinge as 'n hele gesin saam te doen.	1	2	3	4	5

2. Family Crisis Oriented Personal Evaluation Scales (F-COPES)

INSTRUCTIONS : First, read the list of "Response Choices" one at a time. Second, decide how well each statement describes your attitudes and behaviour in response to problems or difficulties.

If the statement describes your response very well, then select the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all, then select the number 1 indicating that you STRONGLY DISAGREE; if the statement describes your response TO SOME DEGREE, then select number 2, 3 or 4 to indicate how much you agree or disagree with the statement about your response.

- | | | | |
|---|----------------------------|---|---------------------|
| 1 | Strongly disagree | 2 | Moderately disagree |
| 3 | Neither agree nor disagree | 4 | Moderately agree |
| 5 | Strongly agree | | |

When we face problems or difficulties in our family, we respond by:

- ___ 1. Sharing our difficulties with relatives
- ___ 2. Seeking encouragement and support from friends
- ___ 3. Knowing we have the power to solve major problems
- ___ 4. Seeking information and advice from persons in other families who have faced the same or similar problems
- ___ 5. Seeking advice from relatives (grandparents, etc.)
- ___ 6. Seeking assistance from community agencies and programs designed to help families in our situation
- ___ 7. Knowing that we have the strength within our own family to solve our problems
- ___ 8. Receiving gifts and favours from neighbours (e.g. food, taking in mail, etc.)
- ___ 9. Seeking information and advice from the family doctor
- ___ 10. Asking neighbours for favours and assistance
- ___ 11. Facing the problems "head-on" and trying to get a solution right away
- ___ 12. Watching television
- ___ 13. Showing that we are strong
- ___ 14. Attending church services

- ___ 15. Accepting stressful events as a fact of life
- ___ 16. Sharing concerns with close friends
- ___ 17. Knowing luck plays a big part in how well we are able to solve family problems
- ___ 18. Exercising with friends to stay fit and reduce tension
- ___ 19. Accepting that difficulties occur unexpectedly
- ___ 20. Doing things with relatives (get-together, dinners, etc.)
- ___ 21. Seeking professional counselling and help for family difficulties
- ___ 22. Believing we can handle our own problems
- ___ 23. Participating in church activities
- ___ 24. Defining the family problem in a more positive way so that we do not become too discouraged
- ___ 25. Asking relatives how they feel about problems we face
- ___ 26. Feeling that no matter what we do to prepare, we will have difficulty handling problems
- ___ 27. Seeking advice from a minister
- ___ 28. Believing if we wait long enough, the problem will go away
- ___ 29. Sharing problems with neighbours
- ___ 30. Having faith in God

INSTRUKSIES : Eerstens, lees die lys van "Voorkeurreaksies" een op 'n slag. Tweedens, besluit hoe goed elke stelling jou houdings en gedrag in reaksie op probleme of moeilikhede beskryf.

Indien die stelling jou reaksie baie goed beskryf, kies nommer 5 om aan te dui dat jy HEELHARTIG SAAMSTEM. Indien die stelling glad nie jou reaksie beskryf nie, kies nommer 1 om aan te dui dat jy GLAD NIE SAAMSTEM NIE. Indien die stelling jou reaksie TOT 'N SEKERE MATE beskryf, kies 'n nommer 2, 3 of 4 om aan te dui in hoe 'n mate jy saamstem, al dan nie, met die stelling oor jou reaksie.

- | | | | |
|---|--------------------------|---|-------------------|
| 1 | Stem glad nie saam nie | 2 | Stem nie saam nie |
| 3 | Het nie 'n standpunt nie | 4 | Stem saam |
| 5 | Stem heelhartig saam | | |

Wanneer ons gesin deur probleme of moeilikhede gekonfronteer word, reageer ons deur:

- _____ 1. Ons moeilikhede met familieleden te deel
- _____ 2. Aanmoediging en ondersteuning by ons vriende te soek
- _____ 3. Te weet dat ons die vermoë het om groot probleme op te los
- _____ 4. Vir inligting en raad te soek by persone in ander gesinne wat al deur dieselfde of soortgelyke probleme gekonfronteer is
- _____ 5. Raad by familieleden (grootouers, ens.) te soek
- _____ 6. Hulp by verenigings vir die gemeenskap (gemeenskapsdienste) en gemeenskapsprogramme, wat ontwerp is om gesinne in ons situasie te help, te soek
- _____ 7. Te weet dat ons die vermoë om ons probleme op te los, binne ons eie gesin het
- _____ 8. Geskenke en gunste van bure te ontvang (bv. kos, pos ontvang, ens.)
- _____ 9. Inligting en raad by die gesinsdokter te soek
- _____ 10. Gunste en hulp van bure te vra
- _____ 11. Die probleme reguit in die gesig te staar en die oplossing onmiddellik te probeer vind
- _____ 12. Televisie te kyk
- _____ 13. Te wys dat ons sterk is
- _____ 14. Kerkdienste by te woon
- _____ 15. Spanningsvolle gebeure as die verloop van die lewe te aanvaar

- _____ 16. Bekommernisse met intieme vriende te deel
- _____ 17. Te weet dat geluk 'n groot rol speel in hoe goed ons daartoe in staat is om gesinsprobleme op te los
- _____ 18. Saam met vriende te oefen om fiks te bly en spanning te verminder
- _____ 19. Te aanvaar dat moeilikhede onverwags voorval
- _____ 20. Dinge saam met familie te doen (byeenkomste, aandetes, ens.)
- _____ 21. Professionele voorligting en hulp vir gesinsprobleme te soek
- _____ 22. Te glo dat ons, ons eie probleme kan hanteer
- _____ 23. Aan kerkaktiwiteite deel te neem
- _____ 24. Die gesinsprobleem op 'n meer positiewe manier te definieer sodat ons nie te veel ontmoedig word nie
- _____ 25. Familielede te vra hoe hulle voel oor probleme wat ons in die gesig staar
- _____ 26. Te voel dat niteenstaande wat ons doen om voor te berei, ons dit moeilik sal vind om probleme te hanteer
- _____ 27. Raad by 'n dominee te soek
- _____ 28. Te glo dat die probleem sal weggaan indien ons lank genoeg wag
- _____ 29. Probleme met bure te deel
- _____ 30. Geloof in God te hê

3. Family Hardiness Index (FHI)

Please read each statement below and decide to what degree each describes your **INSTRUCTIONS** family. Is the statement FALSE, MOSTLY FALSE, MOSTLY TRUE, TRUE, or NOT APPLICABLE about your family?

Please indicate your choice in the appropriate space.

IN OUR FAMILY	False	Mostly False	Mostly True	True	Not Applicable	Official use
1. Trouble results from mistakes we make						
2. It is not wise to plan ahead and hope because things do not turn out anyway						
3. Our work and efforts are not appreciated no matter how hard we try and work						
4. In the long run, the bad things that happen to us are balanced by the good things that happen						
5. We have a sense of being strong even when we face big problems						
6. Many times I feel I can trust that even in difficult times that things will work out						
7. While we don't always agree, we can count on each other to stand by us in times of need						
8. We do not feel we can survive if another problem hits us						
9. We believe that things will work out for the better if we work together as a family						
10. Life seems dull and meaningless						
11. We strive together and help each other no matter what						
12. When our family plans activities we try new and exciting things						
13. We listen to each others' problems, hurts and fears						
14. We tend to do the same things over and over it's boring						
15. We seem to encourage each other to try new things and experiences						
16. It is better to stay at home than go out and do things with others						
17. Being active and learning new things are encouraged						
18. We work together to solve problems						
19. Most of the unhappy things that happen are due to bad luck						
20. We realise our lives are controlled by accidents and luck						

INSTRUKSIES : Lees asseblief elke stelling hieronder en dui aan tot watter mate dit u gesin beskryf. Maak 'n merkie in die toepaslike blokkie. Is die stelling ONWAAR; MEESTAL ONWAAR; MEESTAL WAAR; WAAR, of NIE VAN TOEPASSING, ten opsigte van u gesin?

In ons gesin ...	Onwaar	Meestal Onwaar	Meestal Waar	Waar	Nie van toepassing	Kantoor gebruik
1. Spruit probleme uit foute wat ons maak						
2. Is dit onwys om vooruit te beplan en te hoop, want dinge werk buitendien nie uit nie						
3. Word ons werk en moeite nie waardeer nie, ongeag hoe hard ons probeer en werk						
4. Balanseer die goeie en slegte dinge wat met ons gebeur, mekaar op die lange duur uit						
5. Al staar ons groot probleme in die gesig, het ons 'n gevoel dat ons sterk is						
6. Voel ek dikwels ek kan vertrou dat dinge selfs in moeilike tye sal uitwerk						
7. Alhoewel ons nie altyd saam stem nie, kan ons op mekaar staatmaak om mekaar in tye van nood by te staan						
8. Voel ons dat indien 'n verdere probleem ons tref, ons dit nie sal oorleef nie						
9. Glo ons dat as ons saamwerk as 'n gesin, dinge beter sal uitdraai						
10. Voel die lewe eentonig en sonder betekenis						
11. Strewe ons saam en help ons mekaar, kom wat wil						
12. Probeer ons nuwe en opwindende dinge wanneer ons aktiwiteite beplan						
13. Luister ons na mekaar se probleme, vrese en pyn						
14. Is ons geneig om dieselfde dinge oor en oor te doen...dit is vervelig						
15. Blyk ons mekaar aan te moedig om nuwe dinge en ondervindinge te probeer						
16. Is dit beter om tuis te bly as om uit te gaan en dinge saam met ander te doen						
17. Word dit aangemoedig om aktief te wees en nuwe dinge te leer						
18. Werk ons saam om probleme op te los						
19. Gebeur meeste van die hartseer dinge weens slegte geluk						
20. Besef ons dat ons lewens deur ongelukke en geluk beheer word						

4. Family Problem Solving and Communication Scale (FPSC)

When our family struggles with problems or conflicts which upset us, I would describe my family in the following way:	Vals	Meestal vals	Meestal waar	Waar
1. We yell and scream at each other	0	1	2	3
2. We are respectful of each others' feelings	0	1	2	3
3. We talk things through till we reach a resolution	0	1	2	3
4. We work hard to be sure family members are not hurt, emotionally or physically	0	1	2	3
5. We walk away from conflicts without much satisfaction	0	1	2	3
6. We share with each other how much we care for one another	0	1	2	3
7. We make matters more difficult by fighting and bring up old matters	0	1	2	3
8. We take time to hear what each other has to say or feel	0	1	2	3
9. We work to be calm and talk things through	0	1	2	3
10. We get upset, but we try to end our conflicts on a positive note	0	1	2	3

Wanneer ons gesin worstel met probleme of konflik wat ons ontstel, sal ek my gesin op die volgende wyse beskryf:	Vals	Meestal vals	Meestal waar	Waar
1. Ons gil en skree op mekaar	0	1	2	3
2. Ons respekteer mekaar se gevoelens	0	1	2	3
3. Ons praat dinge deur totdat ons 'n oplossing vind	0	1	2	3
4. Ons probeer hard om te verseker dat gesinslede nie emosioneel of fisies seerkry nie	0	1	2	3
5. Na konflik gaan ons sonder baie bevrediging uitmekaar	0	1	2	3
6. Ons deel met mekaar hoeveel ons vir mekaar omgee	0	1	2	3
7. Ons bemoeilik sake deur te baklei en ou sake weer op te haal	0	1	2	3
8. Ons maak tyd om te hoor wat elkeen te sê het of voel	0	1	2	3
9. Ons probeer hard om kalm te bly en sake deur te praat	0	1	2	3
10. Ons raak ontsteld, maar probeer om ons konflikte op 'n positiewe noot te beëindig	0	1	2	3

5. Family Time and Routine Index (FTRI)

INSTRUCTIONS : First, read the following statements and decide to what extent each of the routines listed below is false or true about your family. Please circle the number (*False (0), Mostly False (1), Mostly True (2), True (3)*) which best expresses your family experiences.

Second, determine the importance of each routine to keeping your family together and strong. Please circle the letters (*NI = Not Important, SI = Somewhat Important, VI = Very Important*) which best express how important the routines are to your family. If you do not have children, relatives, teenagers, etc., please circle *NA = Not Applicable*.

Routines	False	Mostly False	Mostly True	True	How Important to keeping the Family Together and United			
					<i>Not Important</i>	<i>Somewhat Important</i>	<i>Very Important</i>	<i>Not Applicable</i>
1. Parent(s) have some time each day for just talking with the children	0	1	2	3	NI	SI	VI	NA
2. Working parent has a regular play time with the children after coming from work	0	1	2	3	NI	SI	VI	NA
3. Working parent takes care of the children some time almost every day	0	1	2	3	NI	SI	VI	NA
4. Non-working parent and children do something together outside the home almost every day (<i>e.g., shopping, walking, etc.</i>)	0	1	2	3	NI	SI	VI	NA
5. Family has a quiet time each evening when everyone talks or plays quietly	0	1	2	3	NI	SI	VI	NA
6. Family goes some place special together each week	0	1	2	3	NI	SI	VI	NA
7. Family has a certain family time each week when they do things together at home	0	1	2	3	NI	SI	VI	NA
8. Parent(s) read or tell stories to the children almost every day	0	1	2	3	NI	SI	VI	NA
9. Each child has some time each day for playing alone	0	1	2	3	NI	SI	VI	NA
10. Children/teens play with friends daily	0	1	2	3	NI	SI	VI	NA
11. Parents have a certain hobby or sport they do together regularly	0	1	2	3	NI	SI	VI	NA
12. Parents have time with each other quiet often	0	1	2	3	NI	SI	VI	NA
13. Parents go out together one or more times a week	0	1	2	3	NI	SI	VI	NA

14. Parents often spend time with teenagers for private talks	0	1	2	3	NI	SI	VI	NA
15. Children have special things they do or ask for each night at bedtime (e.g. story, good-night kiss, hug, etc.)	0	1	2	3	NI	SI	VI	NA
16. Children go to bed at the same time almost every night	0	1	2	3	NI	SI	VI	NA
17. Family eats at about the same time each night	0	1	2	3	NI	SI	VI	NA
18. Whole family eats one meal together daily	0	1	2	3	NI	SI	VI	NA
19. At least one parent talks to his or her parents regularly	0	1	2	3	NI	SI	VI	NA
20. Family have regular visits with the relatives	0	1	2	3	NI	SI	VI	NA
21. Children/teens spend time with grandparent(s) quite often	0	1	2	3	NI	SI	VI	NA
22. We talk with/ write to relatives usually once a week	0	1	2	3	NI	SI	VI	NA
23. Family checks in or out with each other when someone leaves or comes home	0	1	2	3	NI	SI	VI	NA
24. Working parent(s) comes home from work at the same time each day	0	1	2	3	NI	SI	VI	NA
25. Family has certain things they almost always do to greet each other at the end of the day	0	1	2	3	NI	SI	VI	NA
26. We express caring and affection for each other daily	0	1	2	3	NI	SI	VI	NA
27. Parent(s) have certain things they almost always do each time the children get out of line	0	1	2	3	NI	SI	VI	NA
28. Parents discuss new rules for children/teenagers with them quite often	0	1	2	3	NI	SI	VI	NA
29. Children do regular household chores	0	1	2	3	NI	SI	VI	NA
30. Mothers do regular household chores	0	1	2	3	NI	SI	VI	NA
31. Fathers do regular household chores	0	1	2	3	NI	SI	VI	NA
32. Teenagers do regular household chores	0	1	2	3	NI	SI	VI	NA

INSTRUKSIES : Eerstens, lees die volgende stellings en bepaal dan tot watter mate elk van die roetines waar of onwaar vir jou gesin is: Omkring die syfer (*Onwaar (0), Meestal Onwaar (1), Meestal Waar (2), Waar (3)*) wat jou gesinservaringe die beste beskryf.

Tweedens, bepaal die belangrikheid van elke roetine om jou gesin bymekaar en sterk te hou. Omkring die letters wat die beste aanduiding is van hoe belangrik die roetines vir jou gesin is (*NB = Nie Belangrik, DB = Deels Belangrik, BB = Baie Belangrik*). Indien julle nie kinders, familie, tieners, ens., het nie, moet jy *NVT (Nie Van Toepassing)* omring.

Roetines	Onwaar	Meestal Onwaar	Meestal Waar	Waar	Hoe belangrik om gesin bymekaar en verenig te hou			
					<i>Nie Belangrik</i>	<i>Deels Belangrik</i>	<i>Baie Belangrik</i>	<i>Nie Van Toepassing</i>
1. Ouer(s) het êrens elke dag tyd om sommer net met die kinders te gesels	0	1	2	3	NB	DB	BB	NVT
2. Werkende ouer het op gereelde basis speletyd met die kinders nadat hy/sy terug is van die werk	0	1	2	3	NB	DB	BB	NVT
3. Werkende ouer staan bykans elke dag 'n tydjie af aan die versorging van die kinders	0	1	2	3	NB	DB	BB	NVT
4. Nie-werkende ouer en kinders doen omtrent elke dag saam dinge buite die woning (bv. inkopies, stap, ens.)	0	1	2	3	NB	DB	BB	NVT
5. Gesin het elke aand 'n tyd wanneer elkeen praat of rustig speel	0	1	2	3	NB	DB	BB	NVT
6. Gesin gaan elke week saam na 'n spesiale plek toe	0	1	2	3	NB	DB	BB	NVT
7. Gesin het elke week 'n spesifieke tyd wanneer hulle as 'n gesin iets saam by die huis doen	0	1	2	3	NB	DB	BB	NVT
8. Ouer(s) lees of vertel omtrent elke dag stories vir die kinders	0	1	2	3	NB	DB	BB	NVT
9. Elke kind het elke dag 'n tydjie om op sy/haar eie te speel	0	1	2	3	NB	DB	BB	NVT
10. Kinders/tieners speel daaglik met vriende	0	1	2	3	NB	DB	BB	NVT
11. Ouers het 'n sekere stokperdjie of sport wat hulle gereeld saam beoefen	0	1	2	3	NB	DB	BB	NVT
12. Ouers bring heel dikwels tyd bymekaar deur	0	1	2	3	NB	DB	BB	NVT
13. Ouers gaan een of meer kere per week saam uit	0	1	2	3	NB	DB	BB	NVT
14. Ouers spandeer dikwels tyd met tieners vir privaat gesprekke	0	1	2	3	NB	DB	BB	NVT
15. Kinders het spesiale dinge wat hulle doen of vra wanneer hulle gaan slaap (bv. storie, lekker-slaap-soen, drukkie)	0	1	2	3	NB	DB	BB	NVT

16. Kinders gaan omtrent elke aand dieselfde tyd slaap	0	1	2	3	NB	DB	BB	NVT
17. Gesin eet omtrent dieselfde tyd elke aand	0	1	2	3	NB	DB	BB	NVT
18. Die hele gesin eet daaglik een ete saam	0	1	2	3	NB	DB	BB	NVT
19. Ten minste een ouer praat gereeld met sy of haar ouers	0	1	2	3	NB	DB	BB	NVT
20. Gesin besoek die familie gereeld	0	1	2	3	NB	DB	BB	NVT
21. Kinders/tieners bring heel dikwels tyd by die grootouer(s) deur	0	1	2	3	NB	DB	BB	NVT
22. Ons praat met of skryf vir die familie omtrent een keer per week	0	1	2	3	NB	DB	BB	NVT
23. Gesinslede verwittig mekaar wanneer hulle die huis verlaat of terugkom	0	1	2	3	NB	DB	BB	NVT
24. Werkende ouer(s) kom elke dag dieselfde tyd terug van die werk af	0	1	2	3	NB	DB	BB	NVT
25. Gesin het sekere dinge wat hulle omtrent altyd doen as hulle mekaar groet aan die einde van die dag	0	1	2	3	NB	DB	BB	NVT
26. Ons wys omgee en liefde op 'n daaglikse basis aan mekaar	0	1	2	3	NB	DB	BB	NVT
27. Ouer(s) het sekere dinge wat hulle omtrent altyd doen elke keer as een van die kinders oortree	0	1	2	3	NB	DB	BB	NVT
28. Ouers bespreek nuwe reëls met kinders/tieners heel dikwels	0	1	2	3	NB	DB	BB	NVT
29. Kinders doen gereeld huishoudelike take	0	1	2	3	NB	DB	BB	NVT
30. Ma doen gereeld huishoudelike take	0	1	2	3	NB	DB	BB	NVT
31. Pa doen gereeld huishoudelike take	0	1	2	3	NB	DB	BB	NVT
32. Tieners doen gereeld huishoudelike take	0	1	2	3	NB	DB	BB	NVT

6. Relative and Friend Support Index (RFS)

INSTRUCTIONS : Decide for your family whether you: STRONGLY DISAGREE; DISAGREE; are NEUTRAL; AGREE; or STRONGLY AGREE with the statements listed below. **Indicate your choice in the appropriate space.**

We cope with family problems by:	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Official use
1. Sharing our difficulties with relatives						
2. Seeking advice from relatives						
3. Doing things with relatives (get together)						
4. Seeking encouragement and support from friends						
5. Seeking information and advice from people faced with the same or similar problems						
6. Sharing concerns with close friends						
7. Sharing problems with neighbours						
8. Asking relatives how they feel about the problems we face						

INSTRUKSIES : Besluit vir u gesin of u: BESLIS VERSKIL; VERSKIL; NEUTRAAL is; SAAM STEM; of BESLIS SAAM STEM met die stellings hieronder. **Maak 'n merkie in die toepaslike blokkie.**

Ons hanteer gesinsprobleme deurdat ons:	Beslis verskil	Verskil	Neutraal	Saam stem	Beslis saam stem	Kantoor gebruik
1. Ons probleme met familieledede deel						
2. Advies by familieledede soek						
3. Dinge saam met familieledede doen (bymekaar uitkom)						
4. Aanmoediging en ondersteuning by vriende soek						
5. Inligting en advies by mense met dieselfde of soortgelyke probleme soek						
6. Bekommernisse met goeie vriende deel						
7. Probleme met bure deel						
8. Familieledede uitvra oor hoe hulle voel oor die probleme wat ons ervaar						

7. Social Support Index (SSI)

Please rate the following statements as they apply to your family (Tick the appropriate box)	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Official use
1. If I had an emergency, even people I do not know in this community would be willing to help						
2. I feel good about myself when I sacrifice and give time and energy to members of my family						
3. The things I do for members of my family and they do for me make me feel part of this very important group						
4. People here know they can get help from the community if they are in trouble						
5. I have friends who let me know they value who I am and what I can do						
6. People can depend on each other in this community						
7. Members of my family seldom listen to my problems or concerns; I usually feel criticised						
8. My friends in this community are a part of my everyday activities.						
9. There are times when family members do things that make other members unhappy						
10. I need to be very careful how much I do for my friends because they take advantage of me.						
11. Living in this community gives me a secure feeling						
12. The members of my family make an effort to show their love and affection for me						
13. There is a feeling in this community that people should not get too friendly with each other						
14. This is not a very good community to bring children up in						
15. I feel secure that I am as important to my friends as they are to me						
16. I have some very close friends outside the family who I know really care for me and love me						
17. Member(s) of my family do not seem to understand me; I feel taken for granted						

Evalueer asseblief die volgende stellings soos van toepassing op u gesin (Merk die toepaslike blokkie)	Verskil beslis	Verskil	Neutraal	Stem saam	Stem beslis	Kantoor gebruik
1. Indien ek nood sou ervaar, sal selfs mense in hierdie gemeenskap wat ek nie ken nie, bereid wees om te help						
2. Ek voel goed oor myself as ek opofferings maak en tyd en energie bestee aan lede van my gesin						
3. Die dinge wat ek vir lede van my gesin doen en hulle vir my doen laat my deel van hierdie baie belangrike groep voel						
4. Mense hier rond weet dat hulle hulp van die gemeenskap kan kry indien hulle in die moeilikheid is						
5. Ek het vriende wat my daarvan bewus maak dat hulle my waardeer vir wie ek is en wat ek kan doen						
6. Mense in hierdie gemeenskap kan op mekaar staatmaak						
7. Lede van my gesin luister selde na my probleme of bekommernisse; ek voel gewoonlik gekritiseer						
8. My vriende in hierdie gemeenskap is deel van my alledaagse aktiwiteite						
9. Daar is tye wanneer gesinslede dinge doen wat ander lede ongelukkig maak						
10. Ek moet baie versigtig wees hoeveel ek vir my vriende doen, want hulle maak misbruik van my						
11. Om in hierdie gemeenskap te woon, gee my 'n gevoel van sekuriteit						
12. Die lede van my gesin doen moeite om hul liefde en toegeneentheid vir my te wys						
13. Daar is 'n gevoel in hierdie gemeenskap dat mense nie te vriendskaplik met mekaar moet raak nie						
14. Hierdie is nie 'n baie goeie gemeenskap om kinders in groot te maak nie						
15. Ek voel versekerd dat ek net so belangrik vir my vriende is as hulle vir my						
16. Ek het 'n paar baie goeie vriende buite die gesin wat ek weet regtig vir my omgee en my liefhet						
17. Dit lyk of lede van my gesin my nie verstaan nie; ek voel asof ek vanselfsprekend aanvaar word.						

Addendum G: Consent form

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**STELLENBOSCH UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH**

Resilience in families caring for a family member diagnosed with dementia

You are invited to participate in a research project conducted by Melanie Deist through the Faculty of Arts and Social Sciences at the University of Stellenbosch. This study – which forms part of Ms Deist's Masters dissertation – will explore the characteristics and resources families, who are currently taking care of a family member diagnosed with dementia, use in an attempt to adapt to their situation.

We are currently looking for volunteers from the Cape Metropolitan area to participate in this study. Participants must fit the following criteria:

1. a family member has been diagnosed with dementia;
2. the diagnosis had been made at least one year previously;
3. the symptoms of the dementia is moderate to profound;
4. the **spouse or adult child** of the dementia patient acts as the patient's caregiver;
5. the person diagnosed with dementia has been living with the family for at least six months; and
6. the participant is fluent in either English or Afrikaans.

If you do fit this description, please take some time to read the information presented here, which will explain the details of the study. Please feel free to ask the researcher questions regarding anything that you do not fully understand.

1. PURPOSE OF THE STUDY

The aim of this study is to identify, explore, and describe resilience factors that are present in families where patients diagnosed with dementia are cared for by family members. This study will focus on spouses or adult children caring for the dementia patient, since the role of caregiver most often falls on these sub-groups. This study seeks to provide a body of information from which further examination on a larger-scale can commence in regards to this topic. These future empirical studies can in turn be used in the development and evaluation of intervention programs targeting families caring for a family member diagnosed with dementia.

2. PROCEDURES

The data collection phase will commence in February 2012. If you volunteer to participate in this study, we would ask you to do the following things:

- Biographical Questionnaire

Bio-demographic information will be collected using a biographical questionnaire with structured questions regarding home language, socioeconomic status, marital status, family composition, age and gender of the dementia patient, and information regarding the onset and duration of the illness of the dementia patient.

- Quantitative Questionnaires

In an attempt to identify the factors that facilitate the adjustment and adaptation of families caring for a family member who is diagnosed with dementia, participants will be asked to complete seven self-report questionnaires.

- ⇒ The Family Attachment Changeability Index 8
- ⇒ The Social Support Index
- ⇒ The Family Hardiness Index
- ⇒ The Relative and Friend Support Index
- ⇒ The Family Crisis Oriented Personal Evaluation Scales
- ⇒ The Family Problem Solving and Communication Scale
- ⇒ The Family Time and Routine Index

These questionnaires will take an estimated 30 minutes to complete.

- Qualitative Questions

Some participants will be asked to answer two open-ended questions regarding the topic verbally. The responses to these questions will be digitally recorded. The questions focus on the characteristics and/or resources that you think help your family to adapt to caring for a family member who is diagnosed with dementia. We encourage you to be truthful and to use your own words and personal experiences when answering the questions. Only a limited amount of participants will be asked to complete this part of the study, however, and if enough qualitative data has been collected, you will not be asked to do this.

3. POTENTIAL RISKS

In this study, there are no risks involved regarding your physical well-being. However, caring for a family member suffering from dementia could be distressing at times. We thus encourage you to rather focus on the positive and to think about your family's strengths when answering the questions.

If you experience any psychological distress during or after meeting with the researcher, please contact Prof. A.P. Greeff, who is an experienced psychologist who offers counselling free of charge to all individuals who

participated in this study. Alternatively you can contact FAMSA - an organization dedicated to the development of functional family relations. If you prefer to use a professional in private practice, you can contact Benita Raubenheimer or Sheila Faure (sessions will be charged at normal practice rates).

Contact details:

Prof A.P. Greeff: (021) 808 3464; 072 273 3905

Benita Raubenheimer: (021) 423 2944
8 Brunswick Rd, Tamboerskloof, Cape Town

Sheila Faure: (021) 423 2015
8 Brunswick Rd, Tamboerskloof, Cape Town

FAMSA (Cape Town): (021) 447 7951; <http://www.famsa.org.za>

4. POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

There are no personal benefits for the participants of this research study. You will not receive any compensation for being in this research study. By agreeing to take part in this study, however, you will aid in the understanding of the resilience factors families caring for a family member diagnosed with dementia, utilise in an attempt to adapt to their situation. This understanding may bring us one step closer to the development of specialised training programs targeting these families. The general results of the study will be available to all participants on request via email, but no individual feedback will be given.

5. CONFIDENTIALITY

All the data collected in this study will be treated as confidential. In an attempt to maintain anonymity and confidentiality, all participants will be identified through randomly assigned numbers. No information that could later link your responses to you will be recorded on any of the measuring instruments and no record that links your name to your corresponding number will be kept. The digital recordings of the qualitative interview, the typed transcripts, and all other data coded virtually will be stored on a password-protected personal computer that is only used by the researcher. The data will also be stored on a flash drive as backup. The flash drive and measuring instruments completed by the participants will be stored in a locked drawer at the researcher's residence. In addition, no details that could link a participant to the study will be disclosed in the reporting of the results.

6. PARTICIPATION AND WITHDRAWAL

You can choose whether to participate in this study or not. If you volunteer to participate, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to

answer and remain in the study. The researcher may withdraw you from this research if circumstances arise which justify doing so.

7. RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights, or remedies because of your participation in this research study. If you have questions regarding your rights as a research participant, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact:

Principal Investigator:

Ms. M. Deist

Cell: 084 469 3503

Email: mel.deist@gmail.com

Supervisor:

Prof. A. P. Greeff

Department of Psychology, University of Stellenbosch

Tel: 021 808 3464 / 072 273 3905

SIGNATURE OF RESEARCH PARTICIPANT OR LEGAL REPRESENTATIVE

The information above was explained to me by Melanie Deist in [*Afrikaans/English*]. I am in command of this language and I fully understand what the study entails. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study.

Name of Participant

Signature of Participant

Date

Note: This form in no way forces you to participate in this study. You may withdraw from this study even after the form has been signed.

SIGNATURE OF INVESTIGATOR

I, Melanie Deist, declare that I explained the information given in this document to _____
[*name of participant*]. [*He/she*] was encouraged and given ample time to ask me any questions. This
conversation was conducted in [*Afrikaans/*English*].

Melanie Deist

Name of Investigator

Signature of Investigator

Date



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TOESTEMMING VIR DEELNAME AAN NAVORSINGSPROJEK

Veerkragtigheid in gesinne wat 'n familielid versorg wat gediagnoseer is met demensie

U word uitgenooi om deel te neem aan 'n navorsingsprojek van Melanie Deist van die Universiteit van Stellenbosch se fakulteit Lettere en Sosiale Wetenskappe. Hierdie studie - wat deel vorm van Me Deist se Meestersgraadtesis - ondersoek die eienskappe en hulpbronne wat gesinne, wat tans sorg vir 'n familielid wat gediagnoseer is met demensie, gebruik in 'n poging om aan te pas by hulle omstandighede.

Ons is tans op soek na vrywilligers uit die Kaapse Metropolitaanse gebied om deel te neem aan hierdie studie. Deelnemers moet aan die volgende kriteria voldoen:

1. 'n familielid is gediagnoseer met demensie;
2. die diagnose is ten minste een jaar gelede gemaak;
3. die simptome van die demensie is matig tot ernstig;
4. die eggenoot of volwasse kind van die demensie-pasiënt tree op as die pasiënt se versorger;
5. die persoon gediagnoseer met demensie woon al minstens ses maande saam met die gesin;
6. die deelnemer is vlot in Engels of Afrikaans.

As hierdie beskrywing u pas, moet u asseblief 'n tydjie neem om deur hierdie dokument te lees wat uitbrei oor die besonderhede van die studie. Indien u enige vrae het oor die studie of oor iets wat u nie ten volle verstaan nie, kan u gerus die navorser kontak.

1. DOEL VAN DIE STUDIE

Die doel van hierdie studie is om veerkragtigheidseienskappe wat teenwoordig is in gesinne wat familieledede versorg wat gediagnoseer is met demensie, te identifiseer, te ondersoek, en te beskryf. Hierdie studie fokus op die eggenotes en volwasse kinders wat die demensie-pasiënt versorg, aangesien die rol van versorger meestal op hierdie sub-groepe val. 'n Verdere doelstelling van hierdie studie is om toekomstige ondersoeke op 'n groter skaal met betrekking tot hierdie onderwerp aan te moedig. Sulke toekomstige studies sou kon fokus op die ontwikkeling en evaluering van intervensie programme vir gesinne wat sorg vir 'n familielid wat gediagnoseer is met demensie.

2. PROSEDURES

Die data-insamelingsfase sal begin in Februarie 2012. Indien u bereid is om deel te neem aan hierdie studie, sal u gevra word om die volgende te voltooi:

- Biografiese Vraelys

Bio-demografiese inligting sal ingesamel word met gestruktureerde vrae rakende die deelnemer se huistaal, sosio-ekonomiese status, huwelikstatus, gesinsamestelling, die ouderdom en geslag van die demensie pasiënt, en inligting rakende die aanvang en duur van die diagnose.

- Kwantitatiewe Vraelyste

In 'n poging om faktore te identifiseer wat aanpassing aanhelp in gesinne wat sorg vir 'n familielid wat gediagnoseer is met demensie, sal deelnemers gevra word om die volgende vraelyste te voltooi:

- ⇒ Die Family Attachment Changeability Index 8
- ⇒ Die Social Support Index
- ⇒ Die Family Hardiness Index
- ⇒ Die Relative and Friend Support Index
- ⇒ Die Family Crisis Oriented Personal Evaluation Scales
- ⇒ Die Family Problem Solving and Communication Scale
- ⇒ Die Family Time and Routine Index

Hierdie vraelyste sal ongeveer 30 minute neem om te voltooi.

- Kwalitatiewe Vrae

Sommige deelnemers sal gevra word om twee oop-einde vrae mondelings te beantwoord. Hierdie vrae fokus op die eienskappe en/of hulpbronne wat u gesin help om aan te pas by die versorging van 'n familielid met demensie. Ons moedig u aan om eerlik te wees en om u eie woorde en persoonlike ervarings te gebruik wanneer u die vrae beantwoord. Wanneer voldoende antwoorde op die twee vrae bekom is, sal daar nie van latere deelnemers verwag word om ook hierdie twee vrae te antwoord nie.

3. POTENSIËLE RISIKO'S

Hierdie studie hou geen risiko's in vir u fisiese welstand nie. Ons weet egter dat versorging van 'n familielid met demensie soms ontstellend kan wees. Ons moedig u dus aan om eerder te fokus op die positiewe aspekte wat u gesin help om aan te pas en om na te dink oor die sterkpunte van u gesin wanneer u die vrae beantwoord.

Indien u enige sielkundige ongemak ervaar tydens of ná u ontmoeting met die navorser, kontak gerus vir Prof AP Greeff – 'n ervare sielkundige wat berading gratis sal bied aan alle individue wat aan hierdie studie deelgeneem het. Alternatiewelik kan u FAMSAs kontak – 'n organisasie wat professionele dienste lewer in die ontwikkeling van funksionele gesinsverhoudings. Indien u verkies om gebruik te maak van 'n professionele persoon in 'n privaat praktyk, kan u Benita Raubenheimer of Sheila Faure kontak (sessies sal teen normale praktyk pryse gehef word).

Kontakbesonderhede:

Prof AP Greeff: (021) 808 3464; 072 273 3905

Benita Raubenheimer: (021) 423 2944
Brunswickweg 8, Tamboerskloof, Kaapstad

Sheila Faure: (021) 423 2015
Brunswickweg 8, Tamboerskloof, Kaapstad

FAMSA (Kaapstad): 021 447 7951; <http://www.famsa.org.za>

4. POTENSIËLE VOORDELE VIR DEELNEMERS EN/OF DIE SAMELEWING

Daar is geen persoonlike voordele wat deelnemers kan trek uit hierdie studie nie. U sal nie vergoed word vir u deelname nie. Deur deel te neem aan die studie, stel u ons egter in staat om gesinne wat sorg vir familieledes wat gediagnoseer is met demensie en die faktore wat hulle help om aan te pas by hulle situasie, beter te verstaan. Hierdie kennis kan in die toekoms in intervensie programme gebruik word wat spesifiek fokus op gesinne in soortgelyke omstandighede. Die bevindinge van die studie sal per e-pos beskikbaar gestel word aan alle deelnemers wat so versoek, maar geen persoonlike individuele terugvoering sal gegee word nie.

5. VERTROULIKHEID

Al die data wat ingesamel gaan word in hierdie studie sal vertroulik gehou word. Om anonimiteit te handhaaf, sal alle deelnemers geïdentifiseer word deur middel van aangewese nommers. Geen inligting wat verwys na u identiteit sal op die vraelyste aangeteken word nie. Daar sal ook geen rekord gehou word wat u naam verbind met u ooreenstemmende nommer nie. Die digitale opnames van die kwalitatiewe onderhoude, die getikte transkripsies, en alle ander virtuele data sal gestoor word op 'n wagwoord-beskernde persoonlike rekenaar wat slegs gebruik word deur die navorser. Die data sal ook gestoor word op 'n hardeskyf, wat saam met die data wat met die meetinstrumente bekom is, in 'n laai toegesluit sal word by die navorser se woning. Geen persoonlike besonderhede wat die identiteit van deelnemers koppel aan die studie sal in die studie-verslag genoem word nie.

6. DEELNAME EN ONTTREKKING

U kan self kies of u wil deelneem aan die studie of nie. Indien u wel besluit om deel te neem, kan u enige tyd onttrek van die studie sonder enige nagevolge. U is ook geregtig om te weier om sekere vrae te beantwoord. Die navorser mag u egter onttrek uit die studie indien omstandighede dit regverdig.

7. DEELNEMERS SE REGTE

U kan deelname enige tyd staak sonder enige negatiewe gevolge. U word nie forseer om enige wetlike eise of regte op te hef om deel te neem aan hierdie studie nie. Indien u enige vrae het oor u regte as deelnemer in hierdie navorsing, kontak Me Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] by die Afdeling Navorsingsontwikkeling, Universiteit van Stellenbosch.

8. IDENTIFISERING VAN NAVORSERS

Indien u enige vrae het rakende die navorsing kan u gerus een van die volgende individue kontak:

Hoofnavorser:

Me. M. Deist

Sel: 084 469 3503

E-pos: mel.deist@gmail.com

Studieleier:

Prof. A. P. Greeff

Departement Sielkunde, Stellenbosch Universiteit

Tel: 021 8083464 / 072 273 3905

HANDTEKENING VAN DEELNEMER OF REGSVERTEENWOORDIGER

Die bogenoemde inligting was aan my verduidelik deur Melanie Deist in [Afrikaans/Engels]. Ek verstaan hierdie taal en verstaan ten volle wat die studie behels. Ek was 'n geleentheid gebied om vrae te vra en hierdie vrae was beantwoord na my sin.

Ek gee hiermee vrywillige toestemming om deel te neem aan hierdie studie.

Naam van Deelnemer

Handtekening van Deelnemer

Datum

Let wel: Hierdie vorm forseer u nie om deel te neem aan hierdie studie nie. U mag onttrek uit die studie selfs nadat u die vorm onderteken het.

HANDTEKENING VAN NAVORSER

Ek, Melanie Deist, verklaar dat ek die inligting in hierdie dokument verduidelik het aan _____ [*naam van deelnemer*]. [*Hy/sy*] was aangemoedig en genoeg tyd gegee om my enige vrae oor die studie te vra. Hierdie gesprek was in [*Afrikaans/Engels*] gevoer.

Melanie Deist

Naam van Navorser

Handtekening van Navorser

Datum